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How Medical Discourse Can Mobilize Clinical Diagnostics into a Political Condition: A Multimedia Archive of "Leprosy"

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How Medical Discourse Can Mobilize Clinical Diagnostics into a Political Condition:

A Multimedia Archive of "Leprosy"

A Thesis submitted in partial satisfaction of the

requirements for the degree Master of Arts

in Global Studies

by

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June 2019

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June 2019

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by

Heather N. Snay

## ABSTRACT

How Medical Discourse Can Mobilize Clinical Diagnostics into a Political Condition:

A Multimedia Archive of "Leprosy"

by

Heather N. Snay

What happens when a person becomes ill? What is the effect of this process of becoming a patient? What effect, if any, does this have on the individual's psyche? This thesis asks these questions to provide a window into the process we all go through when we become ill and enter the world of medicine. In order to explore the idea of whether or not the moment of diagnosis can cause mental violence to the patient the extreme historical case of Hansen's disease is analyzed. Known to many by its more common term, "leprosy," which will be referred to as Hansen's monstrous metaphor, a multimedia archival analysis is conducted to deconstruct how "leprosy" came to be a monstrous metaphor and what the effect of this is on the patient. Through discursive analysis of historical legislation, fictional narratives, contemporary newspapers and physician reports, as well as analysis of patient narratives or the autopathography the construction of "leprosy" as a monstrous metaphor evoking a socially stigmatizing and dehumanizing condition is revealed. The first chapter, which focuses on the construction of "leprosy" as a metaphor, demonstrates that medical discourse has the potentiality to build a dehumanizing social condition around a clinical diagnostic. It is then, from this social condition, that political action and governance is

justified. As a result, the diagnostic moment becomes laden with not only social implications but political ones as well. The impact of this on the individual is at the heart of what this thesis aims to uncover. The second chapter is then, devoted to analyzing two different autopathographies in an attempt to uncover what a diagnosis of a disease which has been constructed into such a socially and politically laden identity, has on the individual. This is meant not only in relation to their physical health and their social or political positionalities, but to their own individual understandings of their ‘self’ and how this impacts them at the register of the psyche.

This analysis illuminates that the health narrative, or autopathography, should be considered a vital part of medical education in order to encourage holistic practices which focus on the patient as a person. These narratives, from the perspective of the patient, allow the patient’s voice to be heard in a field that so often silences it. These narratives can help close the gap between the patient and the practitioner who is often so focused on the disease, they forget the patient is not a subject, but a human. They forget that the disease is not only in a lab or an examination room, but a lived reality for a person. I analyze two autopathographies, *Olivia: my life in exile in Kalaupapa* by Olivia Robello Breitha (1988) and *Miracle at Carville* by Betty Martin (1950), written by patients who had the biological illness, Hansen’s disease. In this thesis a stark difference is drawn between Hansen’s disease and what, through Susan Sontag’s theory of “illness as metaphor,” this thesis will term as Hansen’s monstrous metaphor, “leprosy” (1978). Through analysis of both Betty’s and Olivia’s narratives it becomes clear that what they suffered from most is the monstrous metaphor “leprosy” which they have been forced to embody. In analyzing their narrations, the voices of Betty and Olivia expose diagnosis as a moment of a psychic rupture. Suddenly, they see their body through the dehumanizing and pathologizing discourse around

“leprosy”. The internal reactions they describe can only be understood as alienation from one’s own body. I argue that diagnosis can be a moment of mental violence. This is not only as a result of the biological ailment, but any social condition which the diagnosis ascribes to the patient’s body as well. As a result, the social condition should also be considered part of that which the patient must contend. Annemarie Mol’s *The Body Multiple* (2002) argues that illness is multiple as it impacts the patient’s life in many different ways, is something different under the microscope in the lab and is yet something else to the nurse and to the doctor. Mol’s work is, therefore, a vital text which I incorporate into my own discussion of why health narratives, as they illuminate this multiplicity of illness, should be part of medical education since the practitioner should account for these multiplicities in caring for the patient.

Additionally, by analyzing this historical extreme case of an illness that has sustained a social imaginary and evokes images of zombies and “lion faces” the potentiality, and therefore, the power of diagnosis over the individual is uncovered as one that has the ability to alienate the ‘self’ from its own body. Therefore, I argue the body is a space from which the ‘self’ can become “unhomed”. By incorporating Homi Bhabha’s notion of cultural “unhoming” the body becomes an unsafe space for the ‘self’ to exist (1994). Ultimately, what this analysis reveals is the moment of diagnosis as a crucial point where the gap between the patient and practitioner must be closed by a holistic approach. This includes accounting for the multiplicity of illness as it is in this fragile moment that the patient is vulnerable to mental violence.

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## **I. Introduction**

This thesis narrates the potentiality of medical discourse to dehumanize and commit mental violence to the psyche of its subject, the patient. To demonstrate this process, I build an archive of the historical extreme case of Hansen's disease to render visible the transformations of its monstrous metaphor, "leprosy".<sup>1</sup> In constructing this narrative arc, I pull from the historical and cultural archives documents that record how "leprosy" was controlled and how it was socially perceived, respectively. Through discursive analysis the narrative pulled from this comparative reading demonstrates how "leprosy" was transformed from a clinical term labeling an illness, to a socially stigmatized metaphor that evoked monstrosity and implied sin. Finally, it shows how, eventually, these social connotations transcribed "leprosy" into a politically charged label capable of justifying biopolitical governance. A diagnosis of Hansen's disease ascribed all the social fear of the metaphor, "leprosy," on to the bodies of those clinically diagnosed. This enabled a powerful form of racialized pathologization to take form which suggests a public mobilization of clinical diagnostics. I then turn to the literary genre of autopathography to add the voice of the patient with Hansen's to this archive. This illuminates not only the lived experience of patients with Hansen's disease, but the process of becoming a patient. As a result, this analysis brings to light how the moment of diagnosis can constitute mental violence and lead to internal alienation which I will argue is akin to Homi Bhabha's notion of "unhoming".

By unhome I reference Bhabha's notion of "cultural unhoming" which he eloquently describes in *The Location of Culture*, as "the unhomely moment [that] creeps up on you stealthily as your own shadow and suddenly you find yourself ... in a state of 'incredulous terror'" (9). I argue, that this moment described by Bhabha can take place in that moment of diagnosis when an individual receives a diagnosis which brings forth from the shadows a monstrous discourse.<sup>2</sup> In this moment they suddenly find themselves inhabiting a space which has been rendered monstrous and thus they are alienated from their own body and experience "incredulous terror". Through this framing I argue all medical discourse has this "unhoming" potentiality. All medicine, due to its intimate relation to the body has the potential to affect that body's psyche and identity. In this thesis I focus on how medical discourse can serve to dehumanize one's body, with particular emphasis on the moment of diagnosis as a kind of psychic rupture altering the body's image so that even the individual 'self' who inhabits it feels a sense of alienation from it. This alienation is the "unhoming" of the 'self' from the body.

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<sup>1</sup> Here archive refers to historical and cultural works that discuss or are related to "leprosy". The historical archive to which I refer contains U.S. government policies and legislation on Hawaii and Louisiana. These documents both assessed the "threat of leprosy" and established Leprosariums to uphold subsequent segregation policies. The cultural archive to which I refer includes a multimediuem collection of newspapers (*The Star*, only in the Louisiana context), fictional narratives (Most significantly, *Shark Dialogues* by Kiana Davenport in the Hawaiian context), and crucially, autopathographies which I will further contextualize and define in this introduction.

<sup>2</sup> By monstrous discourse I refer to the incorporation of animalistic or criminalistic rhetoric with medical discourse in a way which dehumanizes the individual painting them as a figure to be feared. This can be seen in descriptions which describe the face of a patient with Hansen's disease as "lion face" or discuss patients as "suspected lepers" as though they are suspected of a crime.

This extreme case of “leprosy” served to “unhome” patients from their bodies due to its social stigma which meant that the term alone brought to mind monstrous images of mutilated bodies. This social condition then constructed the monstrous figure “the leper” out of patients with Hansen’s disease. Not unlike Mary Shelley’s 1818 fable, *Frankenstein*, where the creature, though his body deems him monstrous, is actually a deeply sensitive person with more humanity than most of the accepted human characters. The patient’s body serves to turn it into a monstrous unhuman figure, the “leper”. Shelley’s fable highlights this interconnection between science, identity and the body through the creature Frankenstein creates. Victor, through his science, through biology, attempts to piece together the human body and reanimate it. However, once he succeeds, he says, “the beauty of the dream vanished, and breathless horror and disgust filled my heart. Unable to endure the aspect of the being I had created, I rushed out of the room” unable to accept the body he, Victor Frankenstein, has constructed (Shelley 60). Although Victor recognizes the human body of this creature, admiring that “his limbs were in proportion” and that Victor himself, “had selected his features beautiful” he cannot identify with it as human (Shelley 59). Consequently, he is unable to accept the humanity he sees reflected back at him in the eyes of the creature explaining, once the eyes open that, “these luxuriances only formed a more horrid contrast with his watery eyes” and therefore, he fears it (Shelley 60). He fears it as what has come to life is ‘other’ than himself, and yet in the eyes he sees a similarity that he cannot understand. To justify this fear, he deems his creation “a miserable monster” and a “demonical corpse to which [he] had so miserably given life” (Shelley 60). This ‘othering’ which the creature faces is emblematic of the ‘othering’ which unfortunately seems innate to human society. I will argue, that biology and medicine while wonderfully beneficial fields, also hold a darker potential as they can be a tool to create, “miserable monsters” and

“demonical corpses” out of the living human body, to dehumanize in order to control that ‘other’ (biological microorganisms or human bodies) which they do not yet understand.

The colonial era is of course one of the most striking and unsettling time periods where this practice of “othering” oppressed entire cultures and peoples in ways which still affect our contemporary world. Not only is “othering” about ostracizing that which is different, but “othering” becomes a tool to oppress those “different” bodies which posed a threat to the colonial empire in one way or another. Physical difference rendered certain bodies vulnerable to dehumanization, constructing them as monstrous in order to remove any agency they might possess. In the case of “leprosy”, a zombie like figure was fabricated and through diagnosis ascribed to bodies in a way that stripped them of any social and political agency. In *Frankenstein*, as the creature is “othered” and dehumanized, he is ostracized and loses any agency he may have had. This construction of a monstrous figure renders the individual devoid of agency as its fabricated monstrosity socially segregates and disempowers it. As previously stated, this is something science has historically assisted in and in many more subtle ways can still serve to construct today of that which it does not understand or that which is different. This legitimizes the fear felt by confronting human difference, but also to disable the potentially threatening body. The point is not to say all science constructs monstrosity, but simply suggest that it has this potentiality.

More specifically, this thesis focuses on the science of biology that leads to medical understandings and subsequently medical discourses on disease and the human body to ask how medicine can dehumanize. Medicine is intricately intertwined with individual psyche’s and their understanding of their ‘self’ as it directly attempts to understand and define the body. Just as science is used as a framework in Shelley’s novel for how Victor constructs a whole body from fragments, the whole body can also be fragmented by science in a way

that deconstructs the individual. This is not only in a theoretical sense but in a very real way as this figurative fragmenting of the body can very literally affect the individual's psyche. Medicine, which deals most intimately with the body constructs and deconstructs the body as it explores, defines and attempts to understand, make the body and its ailments, manageable to the practice of medicine. However, in this fragmenting, it strips the human from the body. As Michel Foucault suggested in *The Birth of the Clinic* (1994), "if one wishes to know the illness from which he is suffering, one must subtract the individual, with his particular qualities" it is therefore, in the nature of medicine to separate the individual from the body to understand the disease (14). Therefore, when one enters the realm of medicine the focus is of course on the disease, the ailment, the body part or fragment of the whole which is causing pain or discomfort.

While this might be necessary, as Foucault points out, in order to understand what illness or ailment is causing the pain, attention must be paid to the fact that this also fragments the individual from their body, the arm, the stomach or the ailing part of the whole. Shouldn't medicine focus or at least account for the patient as a whole human as well? This fragmenting potentiality of medicine should then demand that extreme care be taken in order to ensure that the moment of diagnosis, which should be a moment of salvation to someone in need, does not actually commit mental violence fracturing or rupturing the 'self' from its body.

This is the overarching argument that I will make in this thesis through the historical extreme example of "leprosy". I will analyze this process within the context of Kalaupapa, Molok'ai, Hawaii and Carville, Louisiana. The fear of the bodies in each of these cases was two-fold. One, they represented a biological threat, their bodies had the potential for contagion through a disease which was not understood. Secondly, in the context of Hawaii

these bodies were also seen as a threat to the colonial empire of the United States. I argue that the construction of the metaphorical “leper,” is utilized as a figure to dehumanize and disempower that ‘other’ body. The Hawaiian case, in the form of colonial ideology not only provides reason for the fear of the ‘other,’ but also the fear of the biological ‘other’. The fear of the contagion that is not understood was simultaneously linked to that culturally different, or visibly ‘other’ body. While the Carville case, is different in that this kind of medically supported racialization remained focused on that foreign ‘other,’ not on the Carville patients themselves instead what manifested was a concern and fear of a threat to public health.

In order to delve into an understanding of how this occurs, the following questions are asked, what happens when our bodies become alienating? Or serve an identity that we do not want? Such as when the body betrays our ‘self’ and becomes ill. We turn to medicine. Medicine has an intimate relationship to our body and as a consequence our ‘self’. As medicine is about the body, dealing with it, understanding it and defining it and its ailments, it holds great power over the individual. Therefore, can medical discourses frame and visualize the body in ways that dehumanize patients? How might such framings produce an internal bodily alienation? Can the moment of diagnosis be seen as identity construction? Could the moment of diagnosis constitute a kind of mental violence for the patient? I will assert that the patient is alienated when the body is marginalized or if the particular clinical condition has a formidable social imaginary that is resurrected in the diagnostic moment. In *Black Skin, White Masks* Franz Fanon submits colonial discourses have a violent effect on the psyche of those it oppresses. Fanon argues of the oppressed subject that, “he lives in a society that makes his inferiority complex possible, in a society that derives its stability from the perpetuation of this complex, ... he will find himself thrust into a neurotic

situation” (100).<sup>3</sup> The discourse which the oppressed subjects must use constructs and promotes a society in which it is impossible for their psyche to exist in any other state than oppressed. Medical discourses can also affect the psyche in similar fashion by constructing a body in which it is impossible for the psyche to exist. In thinking of the body as a space in which the mind or the ‘self’ exists anything that serves to separate or alienate the ‘self’ from its body serves to “unhome” it.

To demonstrate this potentiality of medical discourse I argue “leprosy” is Hansen’s disease’s metaphor to intentionally I evoke Susan Sontag’s broader concept “illness as a metaphor” from her infamous *Illness as Metaphor* (1978). This is in order to highlight *how*, as Sontag describes, “the subjects of deepest dread (corruption, decay, pollution, anomie, weakness) are identified with the disease. The disease itself becomes a metaphor. Then, in the name of the disease (that is, using it as a metaphor), that horror is imposed on other things” (58). The disease, in this case, is Hansen’s disease which becomes transfigured into “leprosy”. This metaphorical term, because it evokes unclean, rotting, mutilated and sinful images of a half-dead human body, allows for the instantaneous transcription of monstrosity, or all of that “horror” to be “imposed” onto any patient’s body in the moment of diagnosis.

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<sup>3</sup> This quote is from the 1967 edition of *Black Skin White Masks* translated by Charles Lam Markmann as this translation better serves the argument being made here.

This is an important distinction as throughout my thesis I refer to the biological illness as Hansen's disease while I use the term "leprosy" to denote the social illness. "Leprosy" in this thesis, is a metaphorical term that signifies the dehumanizing discourse and social imaginary that has become associated with Hansen's disease. I make this distinction to emphasize that the mental turmoil these patients experience and relay in their own narratives is the result of the metaphorical aspects of Hansen's disease as opposed to its physical or biological ailments. This signifies the role that medical discourse plays in the lives of the patient and its potential power. From the psychologically violent moment of diagnosis to the lifelong effects of becoming a "leper" I aim to paint a narrative that shows the level of dehumanizing power medical discourse can reach. In the case of "leprosy" animalistic and criminalizing rhetoric was incorporated into the medical discourse framing Hansen's disease in such a light that the monstrous figure of the "leper" emerges with the capacity to legitimize segregation policies of these patients on a global scale.

"Leprosy" has a global imaginary that has led to "leper colonies," or the isolation of patients with Hansen's disease, in nearly every country. The International Leprosy Association which has held 20 different international conferences since the first one in Berlin, 1897, is a testament to the global imaginary of "leprosy". These conferences include patients, practitioners and public health officials from numerous different countries. At these conferences plans of how to attack the "global situation of 'leprosy'" were/are discussed with "Hidden Challenges" (Brussels 2013) and "Unfinished Business" (China 2016) as the most recent titles of these conferences. The 2019 conference to be held in Manila is entitled "Future Challenges" and suggests the relevancy and contemporary importance of "leprosy". During the years of the "leper colonies" the best way to eradicate this threat was decidedly through segregation despite its low contagion rate suggesting the fear around the disease



was more to do with its perceived monstrosity as opposed to its biological threat. Nonetheless, these conferences provided the medical and legal justification for the leprosariums or “leper colonies” on a global scale. However, for this analysis I will focus on two examples of this enacted by the United States in Hawaii Kaluapapa, Molok’ai established in 1865 and Carville, Louisiana established in 1916 as the official leprosarium of the United States.

To do this, a brief history of the term “leprosy” is necessary in order to incorporate its biblical and religious ties. The biblical history of “leprosy” in particular is part of why it has a powerful dehumanizing effect. The term “leprosy” was initially used as an umbrella term in the bible for skin diseases which were considered curses from God (a few examples can be found in Leviticus 14:54-57; 13: 44-46). This situates “leprosy” as more than just another disease. This religious connection legitimized “leprosy’s” threat making it a powerful biopolitical tool as a “leper” was seen as punished by God for sins or immoral behavior. Therefore, the colonizer for example, through labeling native Hawaiians as “lepers,” constructed their bodies to represent the dirty, sinful and immoral connotations associated with the disease. Due to the physical representation of “leprosy” this meant the very appearance of their bodies labeled them as immoral and dirty. This then creates a situation where “[humanity’s] dread is termed a natural response” because who wouldn’t fear something so disgraceful (Gussow 4)? This allowed for the construction of the native Hawaiian or the ‘other’ body as a weak and amoral population, the colonial narrative which serves to provide the alibi for that benevolent colonial power and the dispensation of western medicine and subsequently colonial governance and control.

It is here that I draw on Neel Ahuja’s term “dread life” from his 2016 book *Bioinsecurities* in which he develops “dread life” to capture the “racialized channeling of the

fear of infectious disease” (6). This is particularly evident in the Hawaiian case where disease was a biopolitical tool to frame the Hawaiian body as a threat. Here “leprosy” enables the biological Hansen’s disease to become an access point for biopolitics, because its monstrosity frames the Hawaiian body as a threat. This means the bodies of those with the potentiality for this threat (“leprosy”), in this case the Hawaiian body, is rendered vulnerable to control. It is “leprosy” the metaphor that the patient must contend with and therefore, the metaphorical has become their lived reality. The moment the patient is diagnosed they are submitted to this discourse. The historical and social stigma attached to “leprosy” through the monstrous language that surrounds it is inescapably inscribed on the patient. Suddenly, their bodies are transfigured into this metaphor and they then serve as its living representation.

In order to develop this argument, I combine historical and literary analysis in my first chapter to illuminate how medical discourse alongside its biblical stigma, was used to support the construction of “leprosy” as a monstrous metaphor for Hansen’s disease in the specific cases of Hawaii and Louisiana. The way “leprosy” is described in the historical documents which dictate isolation of “lepers” as necessary to stop this so-called threat and establish “leper colonies”, actually serve to pathologize patients with the disease. The historical documents offer a perspective on how leprosy as a social condition came to be a matter of public concern and therefore to be governed. They provide evidence of the political mobilization of clinical diagnostics. In contrast, the literary texts provide analytic and imaginative reflections on governing with leprosy. They return us to introspective relations to embodied illness.

The rhetoric in the historical documents such as *The Path of the Destroyer* written by Arthur Mouritz, a former physician for the Kaluapapa “leper colony on Molok’ai shows the

contemporary imaginary in Hawaii around “leprosy” in 1916 as fearful and demonizing. A government senate report, also in 1916 entitled *Care and Treatment of Persons Afflicted with Leprosy* is evidence of similar pathologization in the Carville, Louisiana case. From these documents and others analyzed alongside them the construction of the “leper” and “leprosy” as monstrous is established through animalistic and criminalistics rhetoric. For example, rhetoric such as “surveillance,” “suspicion,” and “suspected leper” criminalizing through disease in outlining how to identify a ‘leper’ as though they were a criminal suspected of a crime (Morrow 586; Mouritz 409). Further dehumanization occurs with the adaptation of animalistic discourse. For instance, describing the face of a ‘leper’ as that of a lion. This kind of rhetoric, which lives in the archive as the story of how society was protected from “the seeds of deadly contagion ... imminence of the danger” actually serves as evidence of pathologization (Morrow 588). From this analysis the way in which a disease can be constructed to conjure a monstrous imaginary is shown.

Through this reading of the archive we can see how disease can be used as a colonial tactic. Here disease is a biopolitical tool as Michel Foucault coined in *Discipline and Punish* (1975). Jasbir Puar’s term “debilitation,” from *The Right to Maim* is necessary to go further and suggest that through disease a body can become socially and politically “debilitated” (2017). This is seen in both cases however; the case of Hawaii also highlights a case of racialization through disease as “leprosy” was used to isolate and disempower Hawaiians and their culture in the years before annexation in 1898. I do not mean to suggest that this is how Hawaii was annexed, but rather that it was part of the United States’ policies on the islands during this time period.

Alongside the historical documents of Hawaii’s case I analyze the proliferation of “leprosy” as a metaphor through the representation and incorporation of the figure of the

“leper” in fictional narratives. In my thesis I will demonstrate this by analyzing Kiana Davenport’s 1992 *Shark Dialogues*. In this historical fiction novel Davenport, a Hawaiian descendant, weaves together the story of a family in Hawaii with altering chapters of historical tales about Hawaii’s early history. The focus of this narrative is the Hawaiian family of Pono and Duke who had four daughters, who each had a daughter with a man from a different ethnicity, other than Hawaiian. In this way the novel discusses identity, specifically hybridity as we follow each granddaughter through their inner turmoil as they try to understand who they are. Davenport uses the bodies of her characters to impress upon the reader the intensity of the turmoil they face. Perhaps the largest piece of the granddaughter’s identity struggles comes from the mystery of their heritage. As they have been made to believe that their grandfather, Duke, is dead they have been robbed of their ancestral identity. However, Duke is very much alive, though his existence has been kept a secret as he has “leprosy” and has been isolated on Kaluapapa, Molok’ai. Through this novel Davenport illuminates the effect of the monstrous discourse around “leprosy” on the Hawaiian cultural imaginary.

The monstrosity of “leprosy” has clearly established not just the cultural imaginary in Hawaii but the United States and the world as a whole as many novels have been written which include “leprosy” in some way. From *Moloka’i* by Alan Brennert (2003) to *Bones to Ashes* by Kathy Reichs (2007) and *The Leper* by Steve Thayer (2008) the story of “leprosy” in the U.S. is well supported by fictional works.<sup>4</sup> Other novels such as, *The Samurai’s Garden* by Gail Tsukiyama (1994), *The Pearl Diver* by Jeff Talarigo (2004) and *No Ordinary Day* by Deborah Ellis (2011) demonstrate the global imaginary around “leprosy”

as well.<sup>5</sup> However, while there are many novels written about “leprosy” and Hawaii there are very few written that explicitly tie their stories to Carville. This absence of Carville centered “leprosy” narratives might be the result of a key difference between Kaluapapa and Carville. The Kaluapapa “leper” colony is a colonial context whereas Carville is not. In this way, as mentioned earlier a certain racialization of the Hawaiian body, through Hansen’s disease, can be suggested. It also serves to suggest a fetishization of the “indigenous” or in this case, the Hawaiian ‘other’ as many novels written about Hawaii and “leprosy” are written by individuals otherwise disconnected from Hawaiian culture or heritage.

While there are not many, if any, novels centered on Carville there is a stronger sense of patient agency to advocate and fight to change the monstrosity which Hansen’s disease has become synonymous with through the term, “leprosy”. Therefore, rather than a fictional novel, *The Star*, a patient established and run newspaper will be analyzed as the cultural proliferation in Louisiana and mainland United States. *The Star -- Radiating the Light of Truth on Hansen’s Disease* was established by Stanley Stein in 1941. The goal was to change the stigma around Hansen’s disease by fighting for the removal of “leprosy” from the discourse of the disease. In this way, these publications, through the voices of the patients which they memorialize, reveal the monstrous discourse evoked by “leprosy” as a central part of their illness. These newspapers then show the individual impact of medical dehumanization. It is this register of the individual, the lived experience, that is my ultimate focus.

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<sup>4</sup> These fictional novels are just a few of many written about “leprosy” in Hawaii and in general, the United States. What is significant is that they are written by authors who are not connected in any personal way to “leprosy” in Hawaii or the United States. As a result, these narratives represent the fascination and cultural imagination of “leprosy”.

In order to delve further into how this process of pathologization affects the individual chapter 2 aims to understand what occurs to the individual when, a diagnosis, renders them the subject of medicine's dehumanizing potentiality. I suggest that this is exhibited through autopathographies, patient narratives of their experiences of being ill. From the recent, *When Breath Becomes Air* by Paul Kalanithi (2017) who narrates his life from a promising surgeon to that of a 36-year-old terminal lung cancer patient to the infamous *Cancer Journals* of Audre Lorde (1980) autopathographies are a powerful genre of literature. This thesis looks at Betty Martin's incredible autopathographies of her life with Hansen's disease in Louisiana entitled *Miracle at Carville* (1950) and *No One Shall Ever Know* (1959). Olivia Robella Breitha's autopathography, *Olivia* (1988) who was diagnosed with Hansen's disease in Hawaii and sent to Kalaupapa tells her experience with Hansen's disease. However, what these narratives have in common is their emphasis and visceral reaction in the very moment of their diagnosis. What their stories tell is not only the tale of the physical effects of the disease, but the mental, interior struggle that results from being labelled a "leper". Through this emphasis, discovered through these autopathographies, the experience of Hansen's disease becomes one of a struggle against a monstrous discourse ascribed to the patient's body at the moment of diagnosis. This disease is not only about a physical ailment, but a social pathologization.

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<sup>5</sup> These authors and their narratives represent the global spread of "leprosy" because they include or are written by individuals in numerous countries. Jeff Talarigo is an American writer who lived in Japan and whose novel *The Pearl Diver* is set in Japan. *The Samurai's Garden* by Gail Tsukiyama is also set in Japan. *No Ordinary Day* by Deborah Ellis, who is a Canadian author, is about a young girl who fears the "lepers" in her town in India.

As Anne Husker Hawkins claimed in her 1999 book entitled, *Reconstructing Illness: Studies in Pathography*, “Pathography records the voice of the ill person: it is thus the exemplary illness narrative, the missing part of the patient history” (14). Through my analysis of autopathographies in this work I show that this missing part of the patient’s history is their subjective experience to entering what Susan Sontag calls “the kingdom of the ill” (1). Since the autopathographies written by Betty and Olivia focus mostly on the social illness the metaphor this shows its impact and that in this particular case, the psychological violence which both narratives reveal as happening instantaneously in the moment of diagnosis is the real challenge and turmoil of this disease. This further suggests the relation between the mind/body and that they affect and are affected by each other. In this way, these autopathographies illuminate part of the story of “leprosy” that the historical archive does not. Through their narrations of their illness and experience with medical practitioners and the medical industry as a whole, they add to the archive of illness what medical records do not, the mental and emotional psychological effects of what I will show as the process of becoming a patient. When one becomes ill, they become a patient. As autopathographies demonstrate, as a patient you are the subject of medicine’s discourse and in this way, it has a certain power over you which has the potentiality for dehumanization.

I conduct this research in hopes of signifying the importance of holistic medical approaches and to highlight the dangers of removing the individual, or the human from medicine. Of course, the case of “leprosy” is an extreme and this analysis is insufficient to make such an impact. However, I hope it does suggest that medicine and the way in which the individual’s body is talked about, the way the patient is approached by this medical industry in which we live, is extremely important. Through autopathography the moment of diagnosis will come to be shown as a crucial moment for the patient and one that has the

potential to commit mental violence. I argue this is due to the fact that diagnosis defines the body to the patient as something other than them “selves” which can cause a fracturing between the ‘self’ and the body. It is vital to not only our physical health, but also to our mental health as it has the strength to alter one of the most intimate spaces through which we define our identity, our body.

After all, as seen in Shelley’s *Frankenstein*, the creature comes to say of himself, “I am an unfortunate and deserted creature” as he has been given no choice but to see him ‘self’ in such a monstrous light (119). As he is dehumanized and ostracized, he comes to understand his own body as: “My person was hideous, and my stature gigantic” (Shelley 115). This socially imposed description of his body is akin to that imposed on the patient who is suddenly forced to understand their body as something hideous, something monstrous, when they receive a stigmatizing diagnosis. When the creature asks, “What did this mean? Who was I? What was I? Whence did I come? What was my destination? These questions continually recurred but I was unable to resolve them” he embodies the debilitating inner turmoil that results from dehumanization (Shelley 115). In the case of Hansen’s disease, this dehumanization is perpetrated through medical discourse and becomes violent to the patient’s mind harming the ‘self’ through dehumanizing the body. To decrease this potentiality of medicine a critical shift in medical thought is required to see that a patient is a person, not a subject.



## II. Chapter One: The Construction of “Leprosy” as a Metaphor

When we become ill, we enter “the kingdom of the sick” as Susan Sontag famously claims in *Illness as Metaphor* (3). Our role in society changes, we become a patient. Now subjected to many tests we are told by the doctor what is wrong with our body. This is how we become a patient: a practitioner translates our bodily experience into symptoms which define a disease. It is how we come to know what our feelings mean according to medical knowledge. The doctor analyses the patient in extremely personal ways, yet often in the most dehumanizing manner and discourse. This is the nature of the “medical gaze” as Michel Foucault terms it in *The Birth of the Clinic*; the practitioner “subtract[s] the individual, with his particular qualities” in order to isolate “the course of the disease [so it] is not interrupted or disturbed by the patient” (14). The strategy is to remove the individual from their ill body with the aim of focusing solely on the disease. As explained in *Sex, Gender, and Science* by Myra J. Hird, “the emerging science of anatomy ... transform[ed] the body into detachable pieces” as each part became identifiable as separate (21). Therefore, through the development of anatomy and biology, each individual organ transforms into something that can be fragmented and separated from the individual (23).

The advancements of biology create a deepening of the medical gaze. As the technologies which we use to visualize different layers of the human body advance, so too does the biological gaze. The deeper this gaze can go, the more the body is deconstructed and the higher the potentiality for biocontrol. As Brian Axel explains, “a fragment of a body [comes to be] reconstituted” or inscribed with new meaning, often through violent or demeaning discourse and this dictates the social identity of that whole body (418). If we consider microorganisms, bacteria, and viruses as becoming part of the human body when

they invade that body, then these become a fragment of the body which can be used to dictate the whole body. As microorganisms constitute illnesses, they are the materiality of the disease which the biological gaze identifies as separate and differentiated from that normative body. It is through the fragmenting of this materiality of disease, from the body, which allows the normative ill body to be seen as an abnormality. In this way, the illness which invades the body subjugates it to dehumanizing discourses with the potentiality of control.

Microorganisms, bacteria and other biological matter that pose a threat to the image of the normative human body provide a technology for control of the invaded body. In *Bioinsecurities* Ahuja suggests this "[constitutes] settler bodies and ecologies as an emergent space of technocratic control, rendering them lively domains of warfare" (5). The ill body is then a dangerous space for the individual inhabiting it as it provides its own justification for its dehumanization and segregation from society. The ill body, as a result of the microorganisms which inhabit it and render it ill, then signifies itself as a potential threat to human life and the conception of the normative human figure. Often this is enough to justify the ill person's marginalization and perhaps even segregation from society, allowing medicine to assist in the normative control of bodies. In this fashion, the patient is subjugated to a form of "biopolitics," as coined by Foucault, which reaches the level of "debilitation" suggested by Puar (Foucault, 11; Puar, x). This paper draws on these theorists to suggest that as medicine seeks to create normativity, it can effectually create monstrosity out of ill individuals establishing a pathological 'other'. Disease, then, has the potential to serve as a technology justifying a medical discourse that not only medicalizes an individual's body but serves to dehumanize and, as a result, control it.

This process of medical dehumanization demands a disease that can support a monstrous discourse. The illness must, as Susan Sontag argues in *Illness as Metaphor and AIDS and Its Metaphors* support metaphors of monstrosity (126). This chapter asks how such a metaphor is constructed by looking at the extreme historical case of Hansen's disease and its metaphors as "leprosy". Sontag explains that "being deadly is not in itself enough to produce terror. It is not even necessary, as in the puzzling case of leprosy, perhaps the most stigmatized of all diseases, although rarely fatal and extremely difficult to transmit" (126). It is not the threat of death which underlies "leprosy's" monstrous metaphors, but rather the way in which its microorganisms invade the body that constitute it as monstrous. As Sontag explains, "the most terrifying illnesses are those perceived not just as lethal but as dehumanizing" (126). The visible mutilations from "leprosy" transform the patient's body into a social text on which is inscribed a dehumanizing tale of animality and rotting flesh that society is conditioned to read as monstrosity. This how "leprosy" mobilizes the construction of monstrous metaphors into a politically charged condition. To deconstruct this process, I analyze the policies enacted in Hawaii in 1865 and Carville, Louisiana in 1916 which officially established the treatment and segregation of people with Hansen's disease. By analyzing the rhetoric of these historical documents, I expose the process by which public health officials construct those ill with Hansen's disease as a monstrous "leper" and subsequently how this social condition becomes a political alibi for biopolitical control.

The first case, Hawaii, demonstrates the ability of "leprosy" through its metaphors, to assist in colonial empire building. Frantz Fanon's argument of the role language plays in controlling individuals in *Black Skin, White Masks*, is critical as we look at the colonial discourse involved in Hawaii. I argue that this colonial discourse is strengthened in Hawaii

through the adaptation of “leprosy’s” medically constructed metaphors. These metaphors transformed the native Hawaiian into the monstrous pathological “other,” the “leper,” which supported colonial rhetoric and goals of annexing Hawaii as it led to the segregation of “nearly 8,000 Hawaiian people” (Senthilingam CNN). Therefore, this Hawaiian case shows how disease itself can become a means of governance.

The legacies of colonial discourse persist in the second case of Carville, Louisiana. While this is not a necessarily racialized case, the practice of “othering” and pathologizing the non-normative body cannot be disconnected from the practices of colonization. As there is not the same colonial motivation, this case demonstrates a different desire for control which is linked primarily to humanity’s fear of that which is different, or ‘other’ in relation to the bodily form. In the case of Carville, the racialization remains focused on that foreign body, the body of the ‘other’ from “uncivilized” countries that threaten to bring “leprosy” to the United States. Carville’s historical narrative applies a discourse which framed “leprosy” as a threat to the empire or survival of the United States. Ahuja argues, “contagion often visually and narratively circulate through media in ways that contain risks to empire” (9). Again, the ill body is a dangerous space for the individual but embodies a biological as well as a theoretical threat to the empire’s control. This framing “justifies” the segregation of those with “leprosy” as an act that is essential for the protection of the people of the United States.

However, what is interesting about the case of “leprosy” is the fact that it is not highly contagious or very lethal. Its threat is namely, the way in which it alters the human body. Therefore, both cases expose bodily deformation as one of humanity’s greatest fears which reveals a very rigid concept of what life itself is and how it must be represented by the human body. Any alterations to the normative form of the human body, which allow it

to continue living but do not uphold this human form, threaten societal understandings of what human life is, should be or can be. Sontag points to the mutilation of the face as yet another key way in which certain illnesses rise to the metaphorical level. Here the face is understood as the manifestation of the individual, what defines them as human life:

Our very notion of the person, of dignity, depends on the separation of face from body, on the possibility that the face may be exempt, or exempt itself, from what is happening to the body. And however lethal, illnesses like heart attacks and influenza that do not damage or deform the face never arouse the deepest dread. (Sontag 128)

Alterations to the human form are what is most feared. Especially in the case of “leprosy” where these bodily changes do not immediately cause death. It is the way the disease interacts with the body that determines whether it can rise to the metaphorical. If the face is seen as separate from the body, and as the chief locale of the person’s individuality, the face therefore, represents and embodies self-identity. Then when that space is altered so too is the individual’s identity. Sontag says that this is especially true of illnesses which mutate the human face into something animal-like, or something which can be construed as such, as seen with “leprosy” (129). The human face is marked with signs of “leprosy” as the skin thickens and loses feeling. The visual and chemical make-up of the face changes supporting the imagery of “lion face”. The very part of the human body, which is its core signifier of humanness is altered and now links it to animality.

As these microorganisms provide the initial opening to frame the ill body as a threat, they provide support for dehumanizing discourses. This language of monstrosity transforms “leprosy” from a disease into monstrous metaphors. Just as Frantz Fanon talks about the power of racialized language in *Black Skin, White Masks* to control and dictate the identity of the individual, medical language allows for control of the individual’s identity by

describing their body as a threat. Of language Fanon says, “To speak means to be in a position to use a certain syntax, to grasp the morphology of this or that language, but it means above all to assume a culture, to support the weight of a civilization” (17-18).

Therefore, as the patient must speak this monstrous language, they are forcibly embodying its monstrosity. I argue that the language used in the historical documents which established regulations to control “leprosy” actually served to construct it as monstrous. How they described the ill body, the words used to dictate how to identify and then deal with that ill body forces all of this monstrosity onto the body of the patient. The language of these documents translates Hansen’s disease into the monstrous metaphors of “leprosy”, the patient as its subject is translated into that lived monstrosity.

In order to illuminate this process, I compare documents from two different cases which provide two different perspectives on the process of racialization through disease. The documents analyzed in the Hawaiian case serve as evidence of the process often utilized by colonial powers to frame the indigenous or ‘other’ as backwards, unclean, and in desperate need of help, thereby, creating an alibi for the governance and intervention of the colonizer as though they are the benevolent savior. The Carville case provides a different narrative on this process of racialization through disease. In this case the patient with Hansen’s disease, vulnerable to the monstrous metaphor of “leprosy” is not the racialized ‘other’, but the embodiment of and therefore, the proof of the threat of contagion. With this case, racialization remains focused on that foreign ‘other’ and their potential to threaten public health. The patients at Carville are then evidence that the threat of “leprosy” is real. In this way these patients are not the racialized figure, but the justification of that racialization of the foreign ‘other’. Both of these cases suggest that the moment of diagnosis can be a potential moment of pathologization imbued with political implications.

In this way, I create an archive of how the metaphor of “leprosy” was constructed through the clinical and social imaginaries of monstrosity around the disease in order to turn it into a matter of public concern. As a result, “leprosy” provided an alibi for biopolitical governance. The historical documents in this chapter serve as evidence of how a medical discourse was constructed around “leprosy” in a way that dehumanized the ill body, transforming the patient into a pathological and monstrous “other,” the “leper”. If the historical archive is read for the way in which they record events, not just the events they record, another layer of the story is revealed. This story tells how society shapes and controls the individual. As Georges Canguilhem contends in his essay *Health*, “there is an idea of the body in general ... laid out biologically and medically in progressively verified knowledge” (50). It then follows that medicine plays a key role in this process of understanding what the body is and how it should be perceived in its various forms. The body ill with Hansen’s disease was constructed, in part through the rhetoric of these documents, to be seen as a monstrous threat.

I add literature to this analysis because of its ability to expose the human experience of disease, thus adding the voice of the individual to the archive. Literature also represents the impact of “leprosy” as a monstrous metaphor on the cultural register which demonstrates how it became a social condition. Therefore, I view literary expression as a valuable representation of the impacts of this pathologizing process in our social imaginaries. By this I refer to the role of literature Ari Larissa Heinrich states in *Chinese Surplus* as “representations of the medically commodified body in literature and visual culture can illuminate ... our understanding of the ongoing effects of biopolitical violence in contemporary life” (2). In this case, Kiana Davenport’s *Shark Dialogues* serves as a representation of the metaphors of “leprosy” penetrating the cultural registers in a way that

pathologized the Hawaiian body and still does so in our contemporary times.

### ***A. Hawaii: Disease as Colonial Control***

The colonial tactics of the United States from 1865 to 1969 in Hawaii utilized “leprosy” as disease biopolitics to debilitate Native Hawaiian’s political voice and culture through segregation policies and isolation on the Leper Settlement on Kalaupapa, Molok’ai. As the United States sought to annex the Hawaiian Islands for monetary and military gain the metaphors of “leprosy” provided a biopolitical form of governance. “Leprosy” inscribed its monstrous metaphors directly onto the bodies of the individuals it afflicted rendering them vulnerable to monstrous treatment. Through the discourse enabled by the visibility of “leprosy” on the body, the disease itself became the kind of punishment Foucault describes as moving beyond pain to achieve “a much higher aim”, of not only punishment, but punishment that leads to control and power over the individual (11). Puar in *The Right to Maim*, describes the impact of this kind of control as “debilitation”, the condition of having such stigmatizing identity that the political voice of not just the afflicted individuals, but a culture as a whole is incapacitated.

Colonial introduction of disease not only devastated local indigenous populations but provided a powerful avenue of control for the colonizer. For example, it is estimated that the population of the islands around 1779 at first colonial contact was nearly half a million people, but by 1893 less than 35,000 Native Hawaiians remained (Morrow 582). Additionally, specific stats about the numbers of “lepers” sent to Kalaupapa in Hawaii depict the devastating effects of this disease on the indigenous population, of the 8,000 individuals who were sent to the leper colony Kalaupapa, 90% were of Hawaiian ancestry (Senthilingam CNN). However, what these numbers and facts do not do is tell the story behind these statistics. While there was a higher percentage of indigenous people



contracting Hansen's disease at this time than in the settler population, these numbers also reflect the racialization of that ill Hawaiian body. This is the story which archival and literary analysis can bring to light.

In order to understand this narrative, the term "dread life" is essential. This is Ahuja's term "to describe this racialized channeling of the fear of infectious disease onto optimism regarding the remaking of life through technical interventions" (6). From here it is possible to understand the intentions of the state as one that seeks to control its population through their own bodies, not just a form of biopolitics, but using biomatter to dictate bodily value or the threat of a body. This then supports the control of certain bodily identities. In 1916 Arthur Mouritz, a former physician for the Kalaupapa "leper settlement" on Molokai, published *The Path of the Destroyer* to capture the tale of leprosy in Hawaii before it was lost forever. This text actually captures not the heroic tale of the United States saving humanity from "leprosy", but the oppression and racialization of the Hawaiian people through this disease. Descriptions, such as the following, paint the Hawaiian population as a health risk that threatens the survival of humankind (a dramatization of the "threat of 'leprosy'"") in a way that invokes the colonial fabrication of cultural difference as cultural "backwardness" commonly used to justify control and oppression:

[A] very affable, agreeable and lovable people, just as much as any other on our earth; but in contact with disease, all their desirable traits are seriously discounted by their lack of care, because they endanger all of us 'by failing to obey the most simple rules of health, necessary for their own salvation and self-preservation'". (Mouritz 9)

As a result, the Hawaiian body is racialized through disease. In this way, the colonial state is not an oppressive colonizer, but a protector of life coming in and helping those populations afflicted with "leprosy". The Hawaiian threat of "leprosy" is adapted to conjure a

benevolent savior alibi for U.S. actions in Hawaii.

This image goes beyond just saving the so-called Hawaiian “race”, but as “leprosy clings to and surrounds the unfortunate Hawaiian...because he fails to realize the danger that menaces him ... this being an indisputable fact, then he (the Hawaiian) is the weak link in our chain of national health defense” (Mouritz, 9). Here it is very clearly a Hawaiian problem, but a problem which threatens the rest of humanity as they are the point of vulnerability which must be strengthened for the good of “national health defense”. Ahuja’s work helps to highlight how the militaristic rhetoric frames the Hawaiian body as a threat to national security setting the stage for its segregation to be justified. Through Ahuja’s argument this constructed narrative can be understood as the empire protecting not just the Hawaiian population from itself, but ensuring the survival of the nation and its people. This effectively elevates the Hawaiian body, because of its potentiality as a threat, into “lively domains of warfare” (Ahuja 5). From this the disease has then been transformed, along with those with the disease, into a metaphorical threat to the survival of the nation and its people.

Prince A. Morrow an M.D. writes a piece on *Leprosy and Hawaiian Annexation* in 1897 advising that this disease must be addressed when considering annexing “Hawaii with its leprous population” (590). Morrow argues that with annexation “many lepers would, in their desire to escape Molokai emigrate to this country;” thus the Hawaiian becomes a monstrous threat trying to invade the United States (Morrow 588). Again, this frames the actions to segregate those with Hansen’s disease as the only measure possible to ensure the safety of the greater population. Since “each of these lepers carries with him the seeds of deadly contagion ... imminence of the danger,” letting them walk around freely would mean letting them spread this disease like seeds. (Morrow 588). This not only racializes the Hawaiian but does so in a way which transforms the Hawaiian body itself into a biologically

threatening figure.

Such racialization of the Hawaiian body as a threat relied on mobilizing the heavy historical stigma that “leprosy” carried. Mouritz provides the historical justification for understanding “leprosy” as a monstrous disease when he outlines the history of “leprosy” in Europe. Including this in his history of Hawaii and “leprosy” he suggests the laws of Hawaii were informed by biblical stigma as well as norms from the past, such as medieval ages Europe. For example, “The leper was pronounced, by edict of the Church, unclean; with him no eating, sleeping, contact or marriage was allowed – he was pronounced civilly dead – all these conditions were rigidly enforced on all, by Church laws and papal decretal” (Mouritz 52). This reveals the monstrous metaphor that those with “leprosy” are essentially walking dead, or more akin to zombies than to a living healthy person.

The terms “leper” and “leprous” in turn evoke these kinds of monstrous metaphors. Throughout both of these documents, as these terms are used to refer to those individuals who had Hansen’s disease, they translate their bodies into those monstrous metaphors. This is the level of dehumanization which these individuals faced. They were quite literally not humans, but “lepers”. Their bodies were not just a body, but a “leprous” body. This strips them of their cultural identity as they are not Hawaiians anymore, but “lepers” and thus, they become this monster. Jeffery Cohen in his chapter entitled *Monster Culture (Seven Thesis)* deconstructs the figure of the monster arguing that the many monster bodies are cultural bodies that reflect societies fears and organization (1997). Cohen argue that “through the body of the monster fantasies of aggression, domination, and inversion” are realized and that “the monster awakens one to the pleasures of the body, to the experience of mortality and corporality” (17). The figure of the monster is a construction of societies fears and a result of its desire for control.

Morrow embodies this monstrous imagination when he explains, “Leprosy is the most ancient and the most dreaded of all diseases; in the popular conception it represents the deepest dishonor that human flesh can suffer. The term “leprous” has crept into literature as expressive of all that is most foul, loathsome and unclean” (Morrow, 583). Descriptions of this nature support the metaphor of “leprosy” as a curse. Identifying the power of the single word “leprous,” Morrow emphasizes the word’s ability to convey horror. It is this word which symbolizes all of these monstrous adjectives such as, foul, loathsome and unclean. The word “leper” and “leprous” serve to unify all of these monstrous metaphors of what is actually Hansen’s disease. Therefore, when an individual’s body becomes describable through this term, “leprous” the individual transforms from the patient into this monstrous figure.

This discourse then signifies the Hawaiian body as a monstrous threat. Morrow explains that “they are sent [to Molokai] to die, and sooner or later they fulfill their sad destiny” (Morrow 587). This is their fate, there is nothing more to be done. This kind of rhetoric supports the metaphor that “leprosy” is a curse, a fate that can only result in death, where a person in fact is a “doomed creature” as he calls these patients (Morrow 587). With the word “creature” he strips away any last thread of resemblance to a human and replaces it with the metaphor of a “creature” doomed to a monstrous existence and a merciful death.

The effects of this at the register of the individual, the lived experience of disease biopolitics as a debilitating colonial tool, is demonstrated in Kiana Davenport’s novel, *Shark Dialogues*. A Hawaiian descendant, her fictional historical narrative traces the history of Hawaii and reveals the struggles of Native Hawaiians in understanding their own cultural identity. Throughout the novel this turmoil is directly connected to the bodies the individual characters inhabit as a consequence of the oppressive biopolitical colonial history. The main

patriarch Duke most vividly represents the debilitation caused by “leprosy”. He illuminates the perspective of the individual by expressing the lived experiences of these biopolitical tactics which force one to embody such monstrous metaphors. Davenport’s use of her character Duke’s body to represent the degradation and debilitation of not only himself, but of the Hawaiian community and culture, exposes the biopolitical and debilitation achieved by the colonial tactics of the United States.

These tactics are part of what Puar calls “the debilitating effects of racism;” they become the “stigmatization of bodily difference, racialized bodily difference, often understood as bodily defect, is already at the core of how populations come to be in the first place” (Puar xx). The creation of what certain bodies represent becomes a debilitating tool that defines and marginalizes a population. Through contextualizing *Shark Dialogues* in history, the use of “leprosy” as a biopolitical colonial tactic to debilitate the native population of Hawaii becomes clear. Disease as biopolitical tactics were used by the U.S. to achieve the power necessary to debilitate and gain control of the land, initially for sugar plantations, but eventually for the annexation of the Hawaiian Islands as a US territory, and ultimately, as a state. The Hawaiian islands were completely isolated until 1778, when the British explorer Captain James Cook landed on the islands (Greene 1). His arrival signified the end of Hawaii’s isolation, the beginning of its colonial era and the introduction of new diseases. While the British played an initial role in Hawaii’s colonization, the U.S. became the source of these biopolitical tactics leading to statehood. Therefore, this chapter focuses on the mid 1800s and into the 1900s with the United States as the colonizer enacting leprosy laws and isolating individuals to Kalaupapa on Molok’ai.

In the beginning, the islands were originally populated by Polynesians as early as the 18<sup>th</sup> century A.D. and again in the 12<sup>th</sup> and 13<sup>th</sup> centuries with people from Tahiti (Greene

1). In *Shark Dialogues* this is the bloodline Duke represents, “huge, dark, built like a warrior, with the big, handsome features of pure Polynesians” (Davenport 102). She connects him to the native bloodlines and describes how his own body represents this Hawaiian lineage ensuring his symbolism as Hawaiian culture. It is this image that becomes altered by the colonizer through the metaphors of leprosy which Duke now symbolizes. Her descriptions highlight the significance of the body in relation to identity. Additionally, she described Duke’s “size, his dignity, his passion for the land reminding them of their Hawaianness, their fierce, proud heritage” further making him a metaphor for Hawaiian culture and people (Davenport 106). Again, she signifies the role of bloodline but also highlights the importance of land. As Duke represents these native Hawaiian attributes, he also represents how they become debilitated through the metaphors of leprosy.

Labeling people as “lepers” stripped them of their Hawaiian cultural identity. This cultural title connects individuals to all of its cultural connotations, bloodline and heritage connections. Therefore, without that label those connections are lost as they became “lepers”, diseased and decaying bodies. Those “lepers” were then subjected to not only segregation but to the loss of their culture and land rights as well. Ultimately, this meant a loss of power, debilitation, for the native Hawaiians. In this sense, “leprosy” became a biopolitical governmentality tactic to debilitate the entire Hawaiian culture. Anyone labeled a “leper”, was seen as punished by God for sins or immoral behavior. Therefore, the colonizer, through labeling native Hawaiians as “lepers”, translated Hawaiian bodies into figures of “leprosy’s” monstrous metaphors. Due to the visual nature of “leprosy” this meant the very appearance of their bodies labeled them as immoral and dirty. This then creates a situation where “[humanity’s] dread is termed a natural response” because who wouldn’t fear something so disgraceful, after all it is a punishment from the almighty God (Gussow

4). Hawaiian bodies become defective in society's eyes. Even God was punishing them. Therefore, their own bodies serve to debilitate the very individuals who inhabit them. This effectively debilitated their ability to act within society as their very bodies were taboo. "Leprosy" now effectively inscribed their bodies with not only disfiguration but the stigmas which that disfiguration represented in the social imaginary.

Kiana Davenport expresses the pain of this dehumanization with the vivid language she uses to describe Duke's diseased body. "Patches running to mold, ears bloated ... face thickening like elephant skin. Nerve ends dead, he probed decay, occasioning a moist, flesh avalanche" (114). Even though the body does not actually decay and melt away, this is the image constructed of diseased Hawaiians. This image frames the bodies of Hawaiians as decaying and grotesque, something to stay away from until they died. Duke represents this belief as well when he describes himself as "[h]alf blind. Ears twisted like green peppers. One hand clawed. One hand gone. Toeless feet. Legs cratered nightmares. Scarred. Twisted. Humped and wrinkled like an ape" (Davenport 343). Here Davenport suggests this stigma was so powerful it could permeate the way Hawaiian's viewed their own bodies. This speaks to the deep psychological impact that this discourse achieved. Duke views his own body through the stigmas it represents and even understands himself as animal like. The comparisons to animals here and throughout the novel demonstrate a kind of mental violence and degradation made possible through the monstrous metaphors of "leprosy" which include dehumanizing comparisons to elephants, apes, and pigs.

From these animalistic metaphors of leprosy, a moral and mental degradation of individuals has the potentiality to debilitate an entire family and even culture as the individual feels they bring shame as well as monstrosity and the threat of infection to their bloodlines. This meant that as "leprosy" deformed their bodies it broke apart their families,

their bloodlines and this in turn debilitated the culture. Davenport demonstrates through Duke's desire to hide his mutilated body from his kin out of shame. When Duke realizes he will be revealed to his kin his shame is evident "and all across the settlement, across the lone peninsula, they heard his scream. The tortured scream of generations. Of people mutilated, cast out of the world. It was a cry for mercy, a cry for rage. A cry for all the voiceless victims lying in their graves" (Davenport 342). This is the power of leprosy as a biopolitical tool and it spans generations. The level of shame that is achieved through biopolitics is possible because it turns individual's bodies against themselves, they forcibly embody that which is evil.

The colonizer didn't simply diagnose "lepers" but created them. The pain, the sin, the mutilation is represented through Duke's body because the colonizer constructed the Hawaiian body to represent those stigmas. As Puar suggests with her debilitation theory, racialized bodies are created as defective through their differences (xx). Here the colonizer used leprosy as a tool to marginalize those differences. This took the stigma of leprosy and moved it to the bodies of Hawaiians. The Hawaiian difference was attacked by the colonizer with leprosy which made "power visible on the body" as the very mutilation of Hawaiian bodies made them vulnerable to the colonizer (Puar x). Their mutilation allowed the colonizer to control them. This results in Duke's cries "for mercy" and "for rage" and "the tortured scream of generations" (Davenport 342). It is this extreme stigmatization, legitimized through the language of government documents, that Hawaiian bodies were made vulnerable to the trope of the leper. This criminalistics and animalistic rhetoric used in these documents erased the human signifiers in the bodies of the patients and legitimized the leper colony on Molok'ai which allowed for the capture, isolation, and imprisonment of these afflicted individuals. This process illuminates even more of how the criminalistic and



animalistic metaphors of leprosy were established but also used to legitimize inhumane treatment.

Morrow's document on the annexation of Hawaii serves as evidence of this stigmatization of the bodies of Hawaiians afflicted with leprosy, "Observation proves conclusively that every leper is a possible source of danger to all with whom he may come into intimate and prolonged contact" (Morrow 585). These individual's bodies represented a danger that must be isolated to protect society. Morrow goes on to dictate the role of the police in containing leprosy, which effectively legitimized the bounty hunting, capture and imprisonment of Hawaiian bodies (586). Police officers were "empowered to bring every suspected leper to the Kalihi reception hospital for examination" (Morrow 586). Here the colonizer makes the body of those they seek to debilitate represent something which they can criminalize and therefore capture, isolate and control. Their bodies make them subject to this treatment.

In this way Hawaiian bodies now worked against their own people representing them as "lepers" which subjected them to segregation and stripped the Hawaiian culture of its people. "An Act to Prevent the Spread of Leprosy" passed in 1865 officially established these biopolitical tactics (Mouritz 33). Through this law the labeling of individual bodies as "lepers" subjected them to inspection, segregation and land loss. This segregation not only removed the diseased bodies from society, but removed power from Hawaiian culture as it effectively removed its people from their lands. This set of laws stated the duty of every police officer was to arrest and deliver any suspected "leper" to the Board of Health and force their medical inspection (Mouritz 33). It is the duty of a police officer to look for and isolate those bodies afflicted with "leprosy" demonstrating that it is an act of protection for the rest of society. This framing legitimizes the segregation process as an act to protect the

greater population. The biopolitical tactics debilitated the Hawaiian body to the point it actually allows for the acceptance of literal hunting and capturing of native Hawaiians.

The Hawaiian body then had the potentiality for “leprous” monstrosity. This threatening potential meant government policies were justified out of a fear of the “leper”. However, a different kind of monstrosity is illuminated when looking at the rhetoric of these policies which dictated how to identify the “leper”. Once the individual was captured they were examined by a board of physicians who would each evaluate the individual alone and then compile their results labelling the individual as either, “clean, a suspect, or a leper” and then they were treated accordingly (Morrow 586). Those determined clean were released as were those labeled as suspects (586). However, the document states, “the suspects [were] kept under surveillance until either the suspicious symptoms have disappeared, or unmistakable signs of leprosy manifest” (586). If one is determined to “be a leper” as the report states, “The pronounced lepers are kept secluded and forwarded by the next boat to the leper settlement to remain there until they die” (586).

The rhetoric of this legislation betrays its own monstrosity when utilizing criminal terms to describe potential patients with “leprosy”. In doing so, the documents serve to criminalize the body afflicted with the disease as though they are found guilty of threatening society. This effectively transcribes the criminal metaphor of “leprosy” onto the Hawaiian body. This criminalization is quite obvious through the application of such terms as “suspect”, “surveillance”, and “suspicion” as they alone evoke a criminal element (Morrow 586; Mouritz 409). Through this criminalizing language the police become empowered as bounty hunters and literally hunt down “lepers” as though they were criminals. This bounty hunting and segregation was acceptable methods of dealing with “lepers” in the eyes of

society as they were not people, let alone Hawaiians, but a threat that needed controlled. Establishing this identity made it acceptable to treat those with “leprosy” in inhumane ways.

Through Davenport’s work the pain and inescapability of this criminalization is captured. This criminalization of “lepers” is embodied in Davenport’s work through Duke and his partner’s capture. “Duke was already handcuffed, gagged, thrown into a large poke like a pig, so they wouldn’t have to touch him. Naked, under lantern light she was probed, nudged with the soles of their boots while they scanned her body for sores” (Davenport 115). The fear of this disease is evident as they avoid touching his partner while inspecting her body to determine if it represents the threat of “leprosy”. Duke’s capture embodies the degradation made possible through “leprosy” which both allows for and causes him to be treated like a pig, like an animal. These individuals were treated as animals as they were hunted down, captured and taken to the leper settlement. This quote perpetuates the criminal aspect discussed above as Duke is handcuffed and gagged. These “leprosy” individuals represented a threat to society and therefore, were treated as criminals. The fear of the disease and its perceived threat to society are present in her novel, “People said Duke was contagious, his workers would spread the sickness to the town” as the disease became visible on his body his workers left and he was forced into hiding (Davenport 328). Instead of a proud Polynesian embodying Hawaianness as earlier described, Duke now represents a contagious disease and the threat of its spread to society. His body now makes him vulnerable to the colonizer’s power, his body is now prey for the bounty hunters.

Again, as the power of leprosy for the colonizer relied on the ability of leprosy to mutilate Hawaiian bodies into the stigma they constructed. This meant the colonizer’s power was literally inscribed on their bodies (Puar x). Duke was “running not just from bounty men but from the message carried in his flesh” (Davenport 114). To take a disease

and create such marginalizing stigma around those afflicted in order to control their bodies, control a population, debilitates the individual and leaves them no escape. Their own bodies are used against them and as Davenport expresses, this is something they cannot outrun. “Leprosy” is writing Duke’s fate on his body, labeling him as a “leper” marking him for isolation. Their “leprous” bodies are a legitimized threat to society and therefore, something that must be eliminated. Through this linguistic framing the discourse within the historical documents have successfully created a sense of danger around the “Hawaiian body”. Davenport captures this process as she describes Duke’s oppression and his understanding of it, as a fate written in his flesh which he can never outrun.

The way in which “leprosy” lends itself to animalistic rhetoric helps construct a language which supports monstrous metaphors such as that of “lion face”. As Sontag points out, “the most dreaded are those [diseases] that seem like mutations into animality (the leper’s “lion face”)” (128-9). This metaphor of the lion is represented in *Shark Dialogues*. It is first a symbolism of pride and strength in order to emphasize the harm done when this image is translated through the monstrosity of “leprosy” into a dehumanizing adjective. At first, “[Duke] had been to them the finest example of the human progression of the Hawaiian race, all that encompassed dignity and valor and fairness. When they took him away, people said a lion got up and left the land...” (Davenport 328). Through this comparison of Duke as a lion Davenport signifies him as a protector and patriarch of Hawaiian lineage and culture. Through the incorporation of this metaphor, the lion, Davenport relays how “leprosy” twisted the Hawaiian’s understanding of their sense of ‘self’ by corrupting their own self-image. For Duke, this specific imagery of a lion becomes altered from an image to be proud of into one to be ashamed of as the medical discourse around “leprosy” uses this metaphor as an animalistic descriptor and signifier for the face of

a “leper”. Through this specific metaphor, Duke’s body is transformed. Through dehumanizing medical discourse, he is separated from his identity as a protector and the perfect embodiment of Hawaianness, into something unhuman, thereby alienating him from his own body.

The historical archive supports such a metaphor when employing language which plays into this ability of “leprosy” to morph the human face into something unrecognizable. In describing how the disease attacks the body “infiltrations occur in the skin... especially prominent about the forehead, cheeks and ears; later these nodules break down, forming ulcerating sores, often they occasion pictures of horrible deformity” (Morrow 584) the archive supports Sontag’s argument that it is *how* the disease attacks the body which allows it to become a metaphorical monstrosity. Describing “leprosy” as infiltrating the skin makes it sound as though the body is literally attacked by a foreign enemy conjuring the image of a threat to not just that body, but the potentiality of this foreign invader for all bodies lest they not be segregated. This is but one metaphor we can attach to this disease. Eventually, this infiltration leads to “horrible deformity,” this is again melodramatic rhetoric used to shape a social imaginary around this disease that is almost unimaginable.

“Leprosy” is described as though it transfigures patients into monsters. In the following quote it is described as something that eats away at the human body, “the nutrition of the skin is interfered with from implication of the nerves, leading to contractions and deformities ... not infrequently there is marked mutilation from the sinking of the nose, the loss of sight, and the dropping off of the fingers and toes, so that only the stumps of the hands remain” (Morrow, 584-585). This description of the disease is not only extremely vivid, but incredibly monstrifying. This portrayal of “leprosy” draws attention to the mutilation it causes to the patient’s face drawing on that fear of facial deformation which

Sontag argues “arouse[s] the deepest dread” within society (Sontag, 128). The descriptions are not only grotesque such as, “the sinking of the nose” and suggesting that fingers and toes “drop off” but they are inaccurate. This kind of description paints a fearful image in the minds of society of a monstrous creature that is created through “leprosy”. While visual deformities occur, body parts do not fall off. These people are not walking zombie-like creatures, despite the discourse in these historical documents. What the discourse in these documents represent, then, is a dramatization of Hansen’s disease in order to support its monstrosifying metaphor “leprosy”. It is not this deformity in and of itself that is fearful, but the way in which society frames it. The idea that the body can be transformed into something monstrous through “leprosy” creates a social condition of fear around Hansen’s disease.

Kiana Davenport in utilizing this metaphor of “leprosy” in *Shark Dialogues* illuminates the monstrosity being forced upon those ill with Hansen’s disease. As seen through her characterization of Duke, this disease not only serves to physically debilitate him but renders him alienated from his body. In the following chapter, I will argue that the individual is in fact unhomed from their body. I expand Homi Bhabha’s notion of cultural unhoming, from *The Location of Culture*, to include an internal separating of the mind from the body. This is shown through Duke as the diagnosis of Hansen’s disease ascribes the monstrous metaphors of “leprosy” to his body erasing everything else. In this way, *Shark Dialogues* reveals the harm done through the medical pathologization which the historical documents, previously analyzed, both constructed and used to justify their segregation policies. Rather than serve as disease control, these documents erased identity from ill individuals which disconnected and unhomed them from their bodies and displaced them from their family and culture.

Without the Hawaiian people the culture was debilitated, and their lands were left vulnerable. The laws enacted the segregation of individuals with “leprosy” while at the same time seizing this opportunity to justify land acquisition. The purchases or exchange of land by the Minister of the Interior, the president of the Board of Health, was justified if it could “seem better adapted to the use of lepers than any land owned by the Government” (Mouritz 33). This law thereby opened the door to “buy” land through the guise of caring for the very people it actually marginalized (Mouritz 33). The land for the leper colony on Molok’ai was seized by the government under the demand for a place to segregate the dangerous lepers (Mouritz 407). This segregation demonstrates of the goal to displace native Hawaiian’s from their land and their people which was possible because the colonizer constructed their leprous bodies as a danger to society. After all, legislation at the time dictated that “Lepers shall not leave the Settlement” in any way unless the Board of Health releases them (Mouritz 410). Therefore, this imprisonment was legitimized through the use of “leprosy” as a biopolitical tactic which created the belief that the bodies of those infected needed to be physically removed from the rest of society for everyone’s safety.

Not only did “leprosy” provide a way for the colonizer to grab land for the segregation of those afflicted bodies, but it provided an opportunity to seize the land owned by those afflicted Hawaiians. Isolation on Molok’ai meant that ultimately their lands were uninhabited. These lands were now owned by a diseased decaying imprisoned body. To handle this the superintendent of public works was empowered to buy all lands that were owned by any person who came to reside on the Leper Settlement at Molokai. (Mouritz 404). In the documentation, it states that if the owner and the superintendent cannot come to an agreement outside “competent and disinterested” parties will be called upon to assess the compensation (407). The laws also state that the commissioners “shall give notice to the

owners, if known to them and resident within the Territory of Hawaii, whose property has been taken or is proposed to be taken” (407). Here the language is very suggestive of the power of the colonizer to “take” the lands and simply leave notice to the owner if they are even known. It also suggests the land can already be “taken” at the time the notice is given. This kind of rhetoric demonstrates the desire of the colonizers to empower themselves to take land thereby demonstrating their true goals of these biopolitical tactics as land control. Ultimately, land control and debilitation (not only achieved through the biopolitical control of “leprosy”) led to the annexation of Hawaii and its eventual statehood.

This empowerment benefitted from the metaphor of “leprosy” and the ability of the colonizer to harness the stigma in support of the debilitating label, “leper”. Through this label, they effectively turned the bodies of Hawaiians into lived manifestations of “leprosy’s” metaphors. “Leprosy’s” metaphors then transformed Hawaiian bodies into technologies of biopolitical control because they had the potentiality for monstrosity. This legitimized their segregation and poor treatment by the colonizer, as in the eyes of society, they were only “lepers”. In this sense, the colonizer not only constructed a new image for native Hawaiians but created the legitimization they needed to debilitate the entire culture. Thus, they turned the bodies of Hawaiians against themselves. Kiana Davenport reveals just how debilitating these biopolitical tactics are for the individual as she depicts Duke’s struggle. Through her text the debilitation of biopolitical tactics which turn one’s own body into its enemy become painfully clear. “Leprosy” was unlike other diseases not just devastate a population but it became a biopolitical tool capable of debilitation and criminal subjection. Davenport’s literary expression brings the individual effect of this to the archive. The immense power of such tactics to debilitate an individual and an entire culture is expressed through pain, shame, mental and physical debilitation so strong they transcend



generations. In this way, the United States effectively used disease to achieve their colonial goals.

***B. Carville: Disease as Control of the ‘other’***

Carville Louisiana represents the “leper colony” in mainland United States. The location of this colony is significant in that it completely alters the motivation and, therefore, the process for the segregation of the patients with Hansen’s disease. Ultimately, the historical narrative of this location is one of protecting the U.S. empire from an outside or foreign threat of contagion. Ahuja argues that the empire will always seek to protect itself from outside threats which include contagion, what is significant is his assertion that the individual body becomes, “a transitional theater of imperial warfare” (1). This conceptualization of the body as a site through which governing powers battle for control and power ties in to Michael Foucault’s biopolitics. The body as a space for battle is not new, in her 1989 *AIDS and its Metaphors* Susan Sontag pleads, “We are not being invaded. The body is not a battlefield. The ill are neither unavoidable casualties nor the enemy” (183). The body of the Hawaiian certainly became a battlefield for U.S. colonial governance as discussed in the narrative rendered visible in the previous analysis. The narrative arc, which is revealed in the analysis to come, of Carville’s history with “leprosy,” will tease out a slightly different condition than that seen in Hawaii. However, the body as a battlefield through which extreme biopolitical governance gains traction and power endures as the common thread between these two cases.

Carville was established in 1916 as The National Leprosarium to isolate citizens with Hansen’s disease within the United States. This location is significant as it meant this space of segregation was not a local site of colonial desires. This is unlike the space of the

Kaluapapa, Molok'ai "leper colony" which was within the Hawaiian Islands and therefore a space subjugated to colonial control of the U.S. government.<sup>6</sup> As a result, the patients and the dehumanizing process of becoming a "leper" as a *citizen* within the United States borders was quite different than the process of becoming a "leper" in Hawaii as a Native Hawaiian. Through "leprosy" the Hawaiian body was racialized as a dangerous threat, one that the U.S. as a colonial savior could use as justification for governance in the islands. Carville patients did not represent this same opportunity for colonial governance and therefore were not racially "othered" in this way. This is not to suggest that the patients of Carville were not demonized, segregated or pathologized as they too faced social ostracization. In fact, the analysis in chapter two which brings in the voice of patient and their experience will demonstrate strikingly similar experiences in this regard. However, the racialization through disease that was a crucial part of the Hawaiian "leper colony" remains focused on that outside "other," the contagion from the outside, in the Carville case.

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<sup>6</sup> Although the bill which established Carville as the National Leprosarium of the United States passed in 1916, due to WWI it was not until 1920 when the Federal government took over the site. Previously, (1892-1894) legislation had been passed to find a site and establish a board to run the Louisiana Leprosarium. See History of National Leprosarium and *The Story of the National Leprosarium* written in 1946 by G.H. Faget and *The Leprosy Problem in the United States* O.E. Denney (DATE) for a more detailed history of the establishment of Carville "leper colony". Due to the stigma around "leprosy" it was difficult to find a site for the leprosarium which did not cause public uproar and protest. Here in lies an area for further analysis as the eventual site of the leprosarium was previously an Indian Camp plantation. The history of this place then begs the inquiry of racialization of space. Traci Brynne Voyles' *Wastelanding* (2015) prompts a discussion of how spaces are racialized and subsequently valued and devalued (rendered pollutable, vacant etc.) a process she conceptualizes as "wastelanding" (10). A further point of inquiry in relation to "leprosy" would be, how might space and disease be intertwined through both racialization and pathologization?

This difference between these two cases is represented in the cultural archive's lack of fictional narratives about Carville. For instance, take this short list of novels beginning with *The Chronicles of Thomas Covenant* a trilogy by Stephen Donaldson (1977), *The Leper* by Steve Thayer (2008), and even Kathy Reichs' famous forensic anthropologist series contains a novel centered on "leprosy" entitled *Bones to Ashes* (2007). These works, among others not listed here, do not contain fictional dramatizations of Carville as a "leper" colony. In contrast, the cultural archive contains numerous narratives which fetishize the idea of that "exotic" history of "leprosy" and Hawaii. This can be understood as evidence of the racialization of the Hawaiian body as it serves as a topic for later cultural fetishization of that diseased 'other' saved by the colonizer. This dramatization is found with the Hawaiian case not only with the previously analyzed *Shark Dialogues*, but with fictional narratives that were not written by anyone with Hawaiian descent. For example, Alan Brennart has several titles on Hawaii and "leprosy," *Moloka'i* (2003) and its sequel *Daughter of Moloka'i* (2019) are just two of those, *Healing Water: A Hawaiian Story* by Joyce Moyer Hostetter (2008), *Molokai* by O.A. Bushnell (1960), and *The Last Aloha* Gaellen Quinn, (2009), serve as just a few examples of how this history is still dramatized. The titles of these works further speak to this fact. This Hawaiian history exists within the cultural imaginary far beyond that of Hawaii as it serves to inspire fictional narratives well beyond its historical time and place.<sup>7</sup> This fetishizing of the exotic 'other', the indigenous or native story that is

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<sup>7</sup> This pattern is emphasized when looking at the topic of "leprosy" within the archive of fictional narratives. There exists numerous novels about "leprosy" in Hawaii as well as other ethnic regions which when put together reveal a pathologization of that "racially" other: Graham Greene's *A Burnt-Out Case* is set in the Congo (1960), J.G. Ballard's *The Crystal World* is set in West Africa (1966), *The Samurai's Garden* by Gail Tsukiyama includes the Chinese figure and the setting of Japan (1995), *The Pearl Diver* by Jeff Talarigo is also set in Japan (2005), *The Leper Compound* by Paula Nangle takes place in Zimbabwe (2008), and *No Ordinary Day* set in India by Deborah Ellis (2011). The wide-ranging dates of publication of this short list alone, which represents just a snapshot of "leprosy's" fictional archive, demonstrate its long and continued place within the larger global cultural imaginary.

rearticulated and retold beyond its people, beyond its historical time and place is the situation of Hawaii and “leprosy”.

The Carville case makes a different impact within the historical archive. It contains more of the pathologized voice whereas this has generally been written out of the Hawaiian case. For example, there are many autopathographies from patients at Carville, in addition to two by Betty Martin which are analyzed in chapter two of this thesis, there is *Alone No Longer* written by Stanley Stein in 1963. Stein is a significant figure in this story as he established *The Star*, in 1941 a newspaper aimed at “Radiating the Light of truth on Hansen’s disease” this statement embodies both the agency of these patients (in comparison to those in Hawaii) as well as the significance of the discourse and the social condition it constructs which then impacts the lived experience of this illness (*The Star*, Vol.1 p.5). Furthermore, their first addition proclaimed:

A prominent Public Health Official remarked, ‘It is unfortunate that the general public is not conversant with the real facts concerning Hansen’s Disease.’ We plan to publish many of these facts and to contradict the mass of misinformation that is constantly published in even the best newspapers and magazines. We realize that we will reach only a small portion of the reading public but, like a pebble thrown into a pond causes ripples in an ever-widening circle, our message will be carried. This is the basis on which we begin the publication of our paper. (*The Star*, 1941, Vol.1 p.5)

This proclamation alone illuminates the difference in agency between these two cases emphasizing the colonial context and the racialization of the patients in Hawaii. The Carville patients have the means to take a stand against their dehumanization through the written word that has also created this metaphorical monster they have been forced to embody.

This section will analyze the senate bill, “Care and Treatment of Persons Afflicted with Leprosy” which established the National Leprosarium in 1916, generally referred to as the Carville “leper” colony, alongside *The Story of the National Leprosarium* (1946) a contemporary history and *Courage!* a newspaper editorial published in the 1941 December edition of *The Star* both written by Dr. G.H. Faget who became the medical director of the hospital in 1940. Together these documents show the construction of the metaphor that is “leprosy” as it was mobilized, through its stigmatizing social image, into a political tool capable of justifying and empowering biopolitical tactics such as segregation.

It is important to note Dr. Faget was an advocate for dismantling the metaphor of “leprosy” and raising awareness around Hansen’s disease to destigmatize it. However, his own rhetoric around “leprosy” evokes the criminalistic and otherwise dehumanizing and monstrous discourse even as he attempts to destigmatize it. Therefore, his own discourse supports the framing of “leprosy” as a threat of contagion from the ‘other’ or as a biological invasion that comes from outside the “civilized” countries like the United States. His writings on “leprosy” are examples of the way this metaphor mobilized a social fear of that contagious foreign ‘other’ and illuminates how disease and the medical discourse around it can be a political alibi for governance. Both of these documents elucidate the way in which disease and its medical discourse, which attempts to understand and frame it, can become highly political when a monstrous or dehumanizing social imaginary exists around it.

Similar to the Hawaiian case, the segregation of those with “leprosy” was framed as a necessary evil which was good for the patients and protected not only their families but the rest of society. Within the space of Carville, the patients, who are citizens, are of course subjected to “leprosy’s” monstrous discourse and pathologized, but not in a way that blames them for the disease. Rather, they have fallen victim to that invading outside threat and as

citizens must be helped for their own safety and the safety of all other citizens. In this way, they were dangerous, feared and dehumanized as they embody the threat for which everyone is potentially at risk. These patients serve as real examples of that otherwise figurative threat of contagion from the ‘other’ or that which lays beyond the protection of the empire<sup>8</sup>. The initial policy which established Carville as the National Leprosarium frames segregation in this way with its title, “A bill to provide for the care and treatment of persons afflicted with leprosy and to prevent the spread of leprosy in the United States” (Care 1). This supports not only the fear of this disease as a threat to life, but does so in a way that demonstrates a fear of this contagion spreading throughout the nation thus, elevating the fear of “leprosy” as it is a threat to the entire nation’s survival. Additionally, it is to provide “care and treatment” for the sick which immediately establishes and justifies this bill as the actions of a benevolent caregiver instead of harsh governance. These documents are an example of the media in Ahuja’s argument that “the racialization of transborder epidemics – the use of media to activate the feeling of bodily risk through the touch of foreign bodies and environments – played an important role in generating public optimism in the imperial state as protector of life” (5).

Additionally, these documents used the biblical imaginary around this disease to bolster the construction of these individuals as people who needed to be saved. For example, the 1916 bill argued of those with Hansen’s disease, that “they frequently have no place of legal residence, and it is therefore impossible to decide which State shall be responsible for their care and treatment” (Care 2). Framing them as wandering threats to public health circulating throughout the country, suggests they are poor, helpless and homeless alluding to

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<sup>8</sup> Within this thesis, the Hawaiian case serves as the example of these ‘other’ bodies that held the potentiality of this threat. The Carville case serves as the example of the “victims” of those so called, “diseased other bodies”. This is a crucial distinction between these two cases.

the metaphor of the wandering, vagabond, or the ostracized leper seen in the middle ages in Europe. This then constructs a need for which these same documents provide an answer. In fact, it was argued that “the treatment which is at present accorded to lepers by the general public is in many instances most inhumane and cruel” (Care 2). Not only are there diseased bodies infecting the country, but these bodies are in desperate need of specialized hospitals where the disease can be segregated and the patient can be cared for appropriately. In this way, these government documents establish a problem and suggest an answer; that the government will care for these poor “unfortunate victims”.

Further framing the “leprosy” problem this 1916 bill pathologizes the bodies of these patients in ways that criminalize them. Section 2 of the 1916 bill dictates that “any person afflicted with leprosy who presents himself or herself for care, detention or treatment or who may be apprehended under authority of the United States quarantine acts, or any person afflicted with leprosy [will be] duly consigned to said home ...” (Care 1-2). Those with Hansen’s disease may submit themselves to “detention” and can be “apprehended” as though they were quite literally criminals. This is similar to the rhetoric seen in the Hawaiian case where the patient and the treatment of them was dictated as follows: “the suspects [were] kept under surveillance until either the suspicious symptoms have disappeared, or unmistakable signs of leprosy manifest” (Morrow 586). Again, these bodies are criminals, they are “suspects” and must be kept “under surveillance” because their bodies are suspicious of containing that threat of “leprosy”.

In response to this, experts were “unanimous in stating that the only known means for effectively controlling the spread of leprosy was segregation. Many of the lepers in the United States wander about the country seeking an asylum, and in this way, they engage in interstate travel and hence fall within the jurisdiction of the Federal Government. They

frequently ....” (Care 2). This clearly frames the patient as a threat, moving around the country spreading the biological invasion of “leprosy”. They have nowhere to go so shouldn’t one be provided for them? A place that will give them the care they need and the protection from the biological threat they harbor within their bodies for the rest of the nation. This directive builds upon the criminal metaphor of the disease discussing the patient just as the law would discuss a criminal who falls under federal jurisdiction by crossing interstate lines.

Clearly these bodies were criminalized but the hypocrisy of the colonial discourse is clear, as this same bill argues against thinking of these patients as common criminals, even as it does so, “The evidence clearly shows that leprosy is a chronic mutilating disease, whose victims inspire such a horror in the public mind that they are ostracized, harried from place to place at times being locked up like common criminals, and at others undergoing treatment which for refinement of cruelty is worse than death itself” (Care 7). The fear of the disease is framed as an unfortunate consequence of the disease itself even as the rhetoric recapitulates and builds up the monstrosity around it. It is the “mutilating disease” itself that has “inspire[ed] such a horror in the public mind” that the government is left no choice but to step in and care for these “victims”. “Leprosy” has become a public fear meaning a diagnosis of this disease brings with it a clinical and social condition which dehumanizes the patient. This rhetoric is capable of simultaneously appearing to step in and deconstruct the monstrous figure of the “leper” while in the same sentence it constructs them as victims stating, “Not only is this the most humane way in which the unfortunate sufferers from a loathsome communicable disease may be treated, but it is also the most economical” (Care 7). There really is no other option for these “unfortunates”. In fact, this is a dire situation which demands government intervention because, “communities are, as a rule, absolutely



unprovided with proper means for the care, segregation, and isolation of lepers” (Care 7). Here the social fear around the disease is backed by experts to be used in support of what becomes biopolitical control of those ill bodies.

As one of those experts, Dr. Faget serves as a key figure who represents this hypocritical simultaneous deconstruction and construction of the monstrous metaphor “leprosy”. Even in his attempt to dismantle the dramatization of this disease, by providing hope for a successful treatment which he does eventually provide, he still works within criminalizing discourse when he explains, “An ever-increasing number of patients is being discharged from leprosariums as ‘arrested cases’ and no longer a menace to the public” (Faget 1871). Here he uses the terms ‘arrested cases’ and ‘no longer a menace to the public’ in an attempt to suggest the disease is not the urgent invasion it has typically been framed to be. However, these words, while commonly used to discuss cases of inactive illness, still evoke their ties to criminal discourse. The individual is no longer a menace. Although, he still suggests that they were a menace or a danger to society.

While Dr. Faget works to destigmatize this disease he does say that, “although there is little danger of contracting leprosy in most civilized nations, where it is a rare disease, it must be admitted that the only sure means of eradicating leprosy from any land is segregation” (Faget 1871). Here Dr. Faget speaks of “eradicating leprosy from any land” undeniably evoking that colonial or empiric desire to protect the territory of the empire from an outside threat. As “leprosy” is not a problem of “civilized” countries the U.S. is presented as a savior, an advanced civilization that would take care of not only its people, but save the ‘other’ from the danger of their own ways. This is seen with the Hawaiian case, where the native Hawaiian was blamed for this disease. Their cultural practices were framed as “unclean” and therefore, the cause of this sinful and dirty disease. Also, during this time

period it was “asserted that leprosy was introduced by a Chinese-man, and consequently was called Mai Pake, or Chinese Sickness, as the Hawaiians had no name for the disease” this suggests “leprosy” as an uncivilized danger of the so-called Orient (Mouritz, 28).<sup>9</sup>

This practice of framing that foreign different body as a danger and something to be controlled is a common practice of colonial governance. However, Carville provides a unique and interesting perspective on how this can be done through the political mobilization of clinical diagnostics. Ascribing these patient bodies as a public health threat incited a “justifiable” fear of the ‘other’ that the government could then use as rationalization for their treatment. In this way “leprosy” became a matter of public concern and therefore, governable. In establishing a social condition where “leprosy” evokes such fear that the majority fear those bodies which contain this disease, the condition then becomes as Ahuja frames it, “a national defense priority” (2). The demand for governance over those ill bodies is now from those governed. Thus, the situation for segregation is a self-fulfilling prophecy. The justification for this practice was constructed by those who desired this governance in the first place, the validation while appearing to come from the public at large, actually grew from the governing power who now is cloaked in the light of that benevolent savior.

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<sup>9</sup> Further exploration of the racialization of “leprosy” can be done in exploring the ways it demonized interracial relations, in particular as it discouraged unions between the white American man and those indigenous or Chinese women. This is yet another way in which “leprosy” was a tool for biopolitical control in relation to reproduction. Examples of this can be seen in *The Path of the Destroyer* by Mouritz.

These discursive tactics are memorialized in “The Care and Treatment Bill”. It was argued that due to the “closer commercial relations existing between the United States and those countries in which leprosy is prevalent, the importation of the disease is very apt to occur” (Care 3). Here it becomes the “importation of disease” not of goods or humans. Further emphasizing “leprosy” as a threat from the outside this same document argues that “in many cases which were brought to the attention of the committee it was clearly shown that leprosy had in this way been contracted and subsequently imported into the United States” (Care 3). Furthermore, “incubation periods of leprosy [are] very long ... [it is] exceedingly difficult to remand these prospective lepers at ports of entry” (Care 7). Therefore, something must be done to protect the points at which the ‘other’ enters the empire as they may be carrying this so called, monstrous disease. Again, this sets up a situation where segregation is not just the only option but the choice necessary to save society. Thus, the alibi for the benign government authority, the only action possible is to quarantine and segregate those threatening bodies. In other words, these bodies were racialized through a diagnosis of “leprosy” which rendered their body a danger and a threat.

This framing meant that the clinical and social imaginary around “leprosy” fueled the “othering” and racialization of foreign bodies. The bodies of the “other,” seen as having the potential for “leprosy” were then easily rendered as monstrous. In the previously quoted section of the 1916 bill it refers to these unknown individuals entering the country as “prospective leper” thus ascribing the body of the outsider with the potentiality for monstrosity and danger to public health by suggesting they could actually be, not human not an immigrant but a hidden “leper”. For example, “At the present time there exists no national institution for the reception and care of lepers in the continental United States. Lepers do not desire to escape from well-conducted leper settlement” (Care 7). In utilizing the term “leper” to denote the subjects of the biological Hansen’s disease, the embodiment of the monstrous figure of the “leper” would be ascribed to the body of the patient in that moment of diagnosis. In using “leprosy” and the specific identifier: “leper,” this suggests that they are something other than human. They are “lepers” a metaphorical figure that invokes images of unclean, sinful, and dirty. In discussing these patients as “lepers” it is clear that these patients have become their disease. They are not individuals, not even patients, but an embodiment of their disease which is socially considered monstrous.<sup>10</sup> It is then possible through diagnosis of “leprosy” to ascribe this undead or walking dead figure to the bodies of the ‘other’ coming in at the ports.

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<sup>10</sup> This claim is further explored and illuminated by the autopathography. I argue that the patient narrative or autopathography can provide a fuller picture of what having a certain illness can mean for the individual lived experience. Here it is also necessary to turn to Ann Marie Mole’s work where she suggests that illness is multiple to get at this very idea that having any disease, in the case of her work atherosclerosis, is more complicated than it may seem. An illness is not just the diagnosis, the clinical symptoms, the clinical numbers or blood test results, the blood under the microscope, but all of these parts combined. Therefore, the totality of these and their cumulative effect on the individual who must live with it represents what that disease is as a lived condition. How does it affect their daily life, how does it change the things they want or can do? These are also parts of the lived experience of illness.

The figure of the monster has been a social tool to render the bodies of those who call into question societal structures which contribute to the governing authority's power. Jeffery Cohen, in his chapter entitled *Monster Culture (Seven Theses)* (1996) argues that "the monster is born only at this metaphoric crossroads, as an embodiment of a certain cultural moment – of a time, a feeling, and a place. The monster's body quite literally incorporates fear, desire, anxiety, and fantasy (ataractic or incendiary)" (4). In the case of the "leprosy" his statement rings true. The fear of that which is not understood, that monstrous disease from the past and that foreign "other," are two fears that fueled the fabrication of the "leper". Cohen furthers his argument saying, that as "[a] construct and a projection, the monster exists only to be read: the *monstrum* is etymologically 'that which reveals,' 'that which warns,' a glyph that seeks a hierophant" (4). That incoming body at the ports, that 'other' native Hawaiian body was framed as a suspicious body through the idea of the monster "leper". The foreign body then was racialized through this disease as a threatening symbol.

In this way, the figure of the "leper" as a monster is very much a political catalyst for biopolitical action. For example, Cohen posits that "monsters born of political expedience and self-justifying nationalism function as living invitations to action, usually military (invasions, usurpations, colonizations), the monster of prohibition polices the borders of the possible, interdicting through its grotesque body some behaviors and actions, envaluing others" (13). The translation of the monstrous social stigma around the metaphor of "leprosy" into a politically charged set of imaginaries rendered its subjects vulnerable to dehumanization and biopolitical control. The Hawaiian case certainly serves as evidence of this practice serving as an invitation to military action. Since "leprosy is a communicable, loathesome, mutilating, chronic disease" (Care 3) it is only logical that such patients be

segregated, their mutilation alone warrants this. It is from these metaphors of “leprosy” that the political agenda is justified. The bodies of those with this disease then become a battlefield for biopolitical control. The moment they are diagnosed with Hansen’s disease they are transfigured into a “leper” and their bodies are inscribed with a social condition that dehumanizes them and supports biopolitical control. This suggests a potential for politicalization of diagnostics and medical discourse.

While we may not be experiencing such an extreme example of this dehumanizing rhetoric today, medical discourse still holds this ability. The way in which doctors and other practitioners speak about the ill individual still has this dehumanizing affect as it turns the body into a medicalized space. Under this framing it is possible for the body to be categorized as either conforming to or in violation of a certain correct body image and body behavior. This is the context where the monster can be fabricated. In this way, the pathological other still exists every time one enters the medical realm. As Susan Sontag so eloquently puts it in *Illness as Metaphor*:

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick.

Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (3)

We become a citizen of the kingdom of the sick as we are forced to become our illness. The rhetoric used to describe our ill body by those practicing medicine transmits to the patient a debilitating sense of their ‘self’. In this moment we are the disease that afflicts us. Hearing our own body discussed in such dehumanizing terms in relation to our ailment or inadequacies impresses these qualities onto our own understanding of our body, suggesting that we *are* these things. We are inadequate. In this way, our understanding of our own

sense of 'self' becomes altered as the image of our body is altered, and so too is the image of our own identity. As a result, we experience an internal alienation because we feel a sense of separation of our psyche from our body.

### III. Chapter Two: Medical Bodily Unhoming

The previous chapter discussed how historical documents, meant to dictate the control of Hansen's disease actually served to translate it, through sensational descriptions using animalistic and criminalistics discourses, into the monstrous metaphor of "leprosy".<sup>11</sup> This analysis suggested a return to the once religiously rooted metaphor of "leprosy" despite advancements in science and the general turn towards scientific facts as our lens through which we narrate and construct knowledges and societies. Drawing on the biblical use of the umbrella term "leprosy," the figure of a "leper" still evokes adjectives such as unclean, dirty, cursed and sinful when applied to the bodies of those with Hansen's disease in our contemporary times. Monstrous images are painted as though the "leper" is a nonhuman creature whose face, for example, is more like that of a lion than a human. This body is also described as half-dead or zombie-like. When fictional novels, as analyzed in the previous chapter, incorporate these metaphors of "leprosy" into their narratives, this dehumanizing figure permeates the cultural registers. As a result, chapter one argued that a monstrous discourse was constructed around Hansen's disease, enabled through medical rhetoric and biblical stigma of the term "leprosy", in order to dehumanize and render certain bodies as a threat and justify their inhumane treatment by framing it as protecting society.

This chapter will focus on what this kind of discourse means for the individual who becomes its subject through diagnosis. I will argue, by turning to Homi Bhabha's concept of cultural "unhoming," from his 1994 *The Location of Culture*, that such monstrous discourse



means the diagnosis becomes a moment of rupture that causes an internal bodily alienation akin to “unhoming”. The body becomes an “unhomely” space for the ‘self’ to exist as it is, in effect, diagnosed as the body of a “leper” not the body of a human. In this way, the bodies of those diagnosed with Hansen’s disease are subjugated to this monstrous discourse as a monstrous pathological ‘other’, a “leper”. Thus, the diagnosis means an instant transformation into not only a new identity, but an unhuman one.

In this chapter I will analyze *Miracle at Carville* by Betty Martin written in 1950 and *Olivia* written in 1988 by Olivia Robello Breitha as autopathographies that speak to the lived reality of Hansen’s disease, or rather its metaphor “leprosy”. This analysis illuminates how, because of the way medicine speaks about the ill body, specifically in cases where it creates a dehumanizing discourse, the moment of diagnosis can be seen as a form of violence to the psyche of the patient as such diagnoses rip the individual from their human identity and forcibly subjects them to a monstrous one. Ultimately, this analysis reveals more than just a historical event which has come and gone. Instead, a greater narrative is discovered which suggests the potentiality of medical discourse to transform the experience of physical illness, into one which is coupled with a metaphorical social illness as well. Here I return to Susan Sontag’s concept of “illness as metaphor” from her 1978 *Illness as Metaphor*, in order to frame “leprosy” and the figure of the “leper” as the metaphors of Hansen’s disease. I argue this metaphor becomes a very real, lived experience for the individual. The “leper” is a figure which exists in the social imaginary as a monstrous

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<sup>11</sup> In this chapter I want to make the distinction between the actual disease and the metaphor applied to it. The actual disease, Hansen’s disease, should be thought of as the biological illness while “leprosy” is a metaphorical term which was originally applied to many different diseases thought to be curses or punishments from God. Clarity of this difference is key to this chapter as through the autopathographies, it is clear that it is the metaphor of “leprosy” which causes the most harm to the individual. In telling the story of their illness both of the analyzed autopathographies actually spend very little time discussing the physical effects of Hansen’s disease. What this reveals, is that changes which occur in their lives were due to “leprosy” (not a “real” disease, but a stigmatizing metaphor), not Hansen’s disease.

creature, therefore, when the individual is diagnosed with Hansen's disease, their body is ascribed with this metaphor of "leprosy" as well. In turn, this erases any other identity as their body is now not just a body, not even their body, but the body of a "leper".

In this way, I turn to Annemarie Mol and Maia Dolphin-Krute who urge us to understand that illness is a lived experience. It is different and multiple for each individual person as Mol, an anthropologist who explores the multiplicity of disease experience through her ethnographic work on atherosclerosis, implores us to realize in *The Body Multiple* written in 2002. The idea that a disease has multiple layers which include more than just the clinical symptoms for the individual is the key aspect of Mol's work which I draw on throughout this chapter. I argue one of these layers, for the individual, is the metaphorical. I then connect this idea to Maia Dolphin-Krute's 2017 book, *Visceral* which pushes for an understanding that because an illness is lived, and not "unimaginable," it is "not a metaphor," providing a crucial critique of Sontag's *Illness as Metaphor* (Dolphin-Krute 47). For Dolphin-Krute the experience of disease cannot be separated from the fact that it is a lived visceral experience even as so much theory attempts to discuss this in the abstract.

I will push this conversation further by combining these theories of the metaphors of illness and the multiplicity of lived experiences together claiming that they are all part of which the patient must contend. This is different than "illness as metaphor" because I am claiming the metaphor of illness, "an unimaginable thing" as Dolphin-Krute suggests, becomes lived for and through the patient (47). While the patient who is diagnosed with Hansen's disease experiences multiple physical symptoms, part of the lived experience of this illness are those symptoms, one might say, of the metaphor the patient comes to suffer from. This metaphor is the monstrous rhetoric and the images the term "leprosy" contains

and evokes, which, through diagnosis, comes to describe their body and turns it into that monstrosity even in their own eyes. Such a diagnosis, then, threatens to erase their identity as a human and replace it with that of a “leper” again, a nonhuman figure. What happens when an individual is delivered a dehumanizing and identity shattering diagnosis like Hansen’s disease? Furthermore, how might the moment of diagnosis be understood as a dehumanization that threatens to alienate the individual from their body and sense of ‘self’?

These questions become answerable through the literary genre of autopathographies. This specific genre of literature consists of patient narratives that narrate what it is like to have certain illnesses. This genre is unique in that it represents the most unmediated or untranslated voice of the patient. Autopathographies can then serve as a space where the patient’s voice can be heard, and therefore, offer a valuable perspective. When entering the realm of medicine, the individual becomes a patient. This is important because the patient is the subject, unlike the individual (a healthy person for this instance), who is the central focus and reason for medicine. However, it is the patient as a subject that becomes the most suppressed through (as the autopathography shows) what can be considered a process of becoming ill. Understanding this experience as a process of becoming ill is crucial because it suggests that illness can cause a change in what the individual is, as they are “becoming” something else.

To break this down a bit further, all people eventually experience discomfort or sensation through their various organs. It is not until the individual tries to verbalize these internal feelings, in order to bring them forth into the external world between oneself and the doctor, that these feelings become symptoms and the individual becomes a patient. The practitioner, nurse and then doctor, can then be understood as translating the individual’s internal experience into an external normalized set of symptoms which eventually, ideally,

link to a specific illness. The individual is now told what those symptoms mean.

Autopathographies, such as those I analyze in this chapter, reveal these steps of becoming ill and show that this stage, the diagnosis, is the point at which they become something ‘other’ than what they were before they entered that room and brought their internal feelings into the realm of the external. In this moment, the individual sees their feelings, translated into symptoms and reflected back to them as an illness which alters their understanding of their internal body. They are told what disease their body represents. In this way, they are medicalized and have become ill. This has the potentiality to distinguish them as pathologically ‘other’ in the eyes of society, as is shown in the case of Hansen’s disease since this diagnosis also ascribes the metaphor of “leprosy” to their body.

This is perhaps the most significant ability of the autopathography, its potential to illuminate diagnosis as a moment when not only the physical disease is ascribed to the body, but its metaphors as well. Through the following autopathographies, I will argue that the moment one is diagnosed with Hansen’s disease its metaphors are brought to life in the form of the patient’s body. This will be evidenced through patient descriptions of their own horror in the moments right after their diagnosis, which refer not to the disease, but to the monstrous metaphorical image of “leprosy” which they now represent. This emphasis on what can be considered the metaphors of Hansen’s disease continues throughout these narratives as both Olivia and Betty spend most of their stories speaking not of the physical effects of Hansen’s disease, but of the damage caused to their lives by “leprosy”.

With this understanding the pain and alienation that results from the patient embodying the metaphor of “leprosy”, can be seen as an alienation from their body as their body has now come to represent that monstrous metaphor. In my reading of the autopathographies in this chapter I argue that when the patient applies the monstrous

discourse of the metaphor to their own body, it is possible to understand this as an alienation from their own body. As now, they too see it, not as their body, but as the body of a “leper”. If we then consider the body as the most intimate home for the ‘self,’ it follows that the individual’s sense of ‘self’ is altered when it is disconnected from its body in such a way.

I argue that this disconnection results in an internal “unhoming”. As the patient is forced to see their body through this monstrous lens, they are forced to apply this language to their own body and it becomes an “unhomely” space. Again, this is where I turn to Homi Bhabha’s development of the term “unhomely” in which he uses it to describe an unsafe or unfriendly cultural space. I expand Bhabha’s notion of “unhoming” to include the body as a space from which one can become “unhomed”. This “unhoming” is the result of the diagnosis transcribing patients into “lepers” as an effect of Hansen’s disease’s translation into the monstrous metaphor of “leprosy”. This results in the patient’s body forcibly embodying that of a monstrous pathological ‘other’. I argue that this renders the body an “unhomely” space for the psyche in which one’s sense of ‘self’ struggles to exist.<sup>12</sup> As a result, I am suggesting that autopathographies serve to emphasize the criticality for a holistic approach in medicine. They show that the patient must be seen as an individual, a person, holistically as a mind/body entity in order to avoid medical dehumanization that results in such trauma to the patient that they are “unhomed” from their own bodies.

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<sup>12</sup> As Rita Charon explains in *Narrative Medicine: Honoring the Stories of Illness*, “[t]he self depends on the body for its presence, its location. Without the body, the self cannot be uttered” (Charon, 87). In this way, the body can be thought of as the space in which the ‘self’ exists. The ‘self’ also defines itself in part, through the body, the space it inhabits. This occurs from how the individual internally sees their own body, what they believe their ‘self’ to be, as well as what they are told their body means. Therefore, “as the body is the proxy for the self ... demeaning or disrespecting the patient’s body demeans and disrespects the patient’s self” (Charon, 86). A diagnosis which turns a patient’s body into that of a “leper” would surely affect the individual’s sense of ‘self’. I argue that “leprosy” is able to do just that. The diagnosis means not only a physical ailment, but the embodiment of a monstrous metaphor. Thus, the individual must live with a disease and its damning stigma as their reality.

Again, due to Hansen's disease's extreme history and its metaphor "leprosy," this chapter will focus on autopathographies of those who became ill with Hansen's disease, and therefore, experienced its monstrous metaphor, "leprosy". Both *Miracle at Carville* by Betty Martin and *Olivia* by Olivia Robello Breitha reveal how the diagnosis, because of the monstrosity attached to the term "leprosy", changed the perception of their body, not only for others, but even for themselves. In fact, even though there is a slight difference in time of diagnosis, publication of their narratives and of course, these women differ in location, their pathographies are shockingly similar in what they reveal and how they choose to tell their stories. Both frame their narratives through an initial before diagnosis and after diagnosis structure emphasizing that there is a dramatic change which occurs at the moment of diagnosis. Since both women also include similar aspects of their lives, describing their families and their love lives as part of their narratives of disease, this suggests that family and love are integral parts of their lived experience of "leprosy" and differ before and after diagnosis.

Additionally, their own use of this dehumanizing rhetoric is apparent in each case and serves to exhibit its debilitating nature in a way which suggests the potentiality of medical discourse to control the individual at the most personal of levels.<sup>13</sup> These similarities, despite a difference in time and location, reveal how this pathologization affects the individual in similar ways no matter where they are. This is not to say the effects result in the same change or impact for all individuals, but rather, that a diagnosis of Hansen's disease, includes a process of pathologization that affects all aspects of one's life, family, love, and psyche although perhaps in different ways, regardless of place or time.

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<sup>13</sup> By debilitate I refer to Jasbir Puar's 2017, *The Right to Maim* in which she defines debility not as an identity, but rather as "a form of massification" which leaves the subject socially and politically debilitated (xvii-xviii).

The structures of Olivia Robello Breitha's and Betty Martin's pathographies reveal this process of diagnosis as one which suddenly turns them into "a leper" altering their lives and their sense of 'self'. Olivia's story begins, as she says, in 1934 and takes place in Hawaii. She bookends her initial chapter entitled, "Growing Up" with the line, "Until the year 1934, my life was ordinary and uneventful" (Breitha 1, 5). Her life was not much to speak of up until this year, 1934 when she would be diagnosed with Hansen's disease, after which she no longer says her "life was ordinary and uneventful" (Breitha 1, 5). Her intentional framing and emphasis on this line signify that year, of her diagnosis, as forever altering the course of her life. Between these lines, Olivia explains that her very typical "family consisted of three sisters, one brother, and [her] parents", they were nothing unusual, but the frame she provides foreshadows this as something which will change in 1934 (1). She continues to flesh out her before diagnosis family life explaining her father worked the land and "grew sweet potatoes, sugar cane, corn, and other vegetables, all for our table" again, her family is nothing out of the ordinary (Breitha 1). She doesn't embellish her descriptions of the life she had before 1934 but frames it very plainly stressing the simplicity and ordinariness of it all. She talks about her siblings, her mother, injuries, and holidays claiming, "those beautiful memories are with me still" (Breitha 1).

Though her life was not picture perfect, nor always happy, as she shows us through a moment of unhappiness when moving to Honolulu and being "very poor during [her] childhood" she still maintains that even in poverty her life was ordinary, "[i]t isn't that we starved or anything" (Breitha 2). Nothing was extreme or unique it was a simple and uneventful life up until 1934 when all changes with her diagnosis. As the metaphors of "leprosy" include this idea that the disease is itself a curse for those who sin, it is significant that Olivia spends her first several pages painting her life as "normal". This speaks to the

metaphor of “leprosy” as a curse since through this narrative of normalcy she erases any potentiality of “sin” in her life and thus eschews this as a cause of her illness.

When remembering home-cooked meals Olivia highlights happiness, “I can still remember how wonderful everything tasted and how we screamed and played in the water” (3). Through these memories, she paints a carefree childhood of good food and summer fun. This contrasts the fabrication of a sinful and unclean life envisioned through the demonizing rhetoric of “leprosy’s” metaphors. She continues, “There were many happy times during my teens” enforcing this emphasis on happiness clear up until, and including, becoming engaged to be married in 1934 (Breitha 3). Opening her autopathography with such emphasis on normalcy, ordinariness, and uneventfulness paints the strongest emotion as happiness. She directly counters the images of unclean, sinful and unhuman by narrating her early life in this way. However, beginning with the line “Until the year 1934, my life was ordinary and uneventful” Olivia foreshadows this year of diagnosis will change all of this (5).

Similarly, Betty Martin opens her narrative just before her diagnosis also giving herself a chance to construct the image of herself and her life as she was before. This before framing in itself points to the idea that there is, for both Betty and Olivia, a story that occurred before “leprosy” and is different from the story that occurs after. Betty’s story takes place in 1928 and begins “[t]he most beautiful Christmas was when I was nineteen and the world was mine” (1). In other words, she had everything to lose. Like Olivia, she frames herself, her world, and family as happy and ordinary. Betty’s “world being New Orleans and its gaiety and the fun of being engaged and in love for the first time” had nothing in sight except cheerful parties, the excitement of engagement and love (1). This is Betty’s



sense of ‘self’ before diagnosis which is a contrast with the rest of her autopathography as she recounts the rest of her life, after diagnosis.

Each of these autopathographies demonstrates that a diagnosis of “leprosy” affects their lives in more than just a physical, personal way. In framing their lives before diagnosis through family and romance they include these as part of what a diagnosis of “leprosy” affects. As both Betty and Olivia highlight family and romance in the beginning of their narratives they reveal how important these things are for them, and they also foreshadow their change. Betty frames her family as happy and close, emphasizing the importance of this by saying, “Our family was large and closely knit. Mamère – Mama’s mother – never failed to telephone each of her eight children each morning inquiring for each grandchild by name” (1). Similarly, Olivia also mentions that her “My maternal grandparents lived below us and we would visit them often. It was so wonderful when we were little” (1). Just as Betty highlights a close-knit family, Olivia also chooses to include this in her very first page of her autopathography as well. The closeness and significance of family is, therefore, something that is not only important to both, but something which is affected by their diagnosis.

Another aspect of their lives that both chose to include is romance. Again, this is in some of the very beginning pages of these narratives stressing its significance in their lives and that it is affected by their diagnosis. For instance, Betty was engaged to be married when she was diagnosed with Hansen’s disease. Her narrative begins with her relationship with Robert, “I think it was on our second date that Robert told me he loved me and intended to marry me someday” (Martin 13). She explains how her love for him grew and that she was ready to marry him, “I found myself dwelling on his many fine qualities, and my interest in other young men was definitely on the wane” (Martin 13). She remembers

herself as happy, engaged and with everything to lose. Similarly, Olivia also mentions that she was engaged to be married before she was diagnosed with Hansen's disease.

Both women recount their lives before diagnosis as young girls in love, engaged to be married, with happy close-knit families. However, after the diagnosis, all of this changes quite drastically and very suddenly. The single moment of diagnosis immediately alters their lives in their entirety forever. Mol argues the impacts of illness on one's life, such as altering their familial and romantic relationships demonstrates the multiplicity of illness (22, 23). Such impacts on the patient's life are not considered part of the definition of disease when in reality they define what, in this case, "leprosy" is for the patient.

After her diagnosis, before Olivia is sent away to Kalaupapa she explains, "I wouldn't be able to see my family every other day that made it so difficult. My mother was heartbroken. Poor, darling Mama. She tried so hard not to cry, but I could see her eyes. They were full of suffering and helplessness" (18).<sup>14</sup> Now her family is taken away. She is separated from that happiness and that close-knit family. This is replaced with hopelessness and isolation. All of this is the lived experience of this illness. For the patient, this is "leprosy," a once happy family separated and brought to "tears" and "helplessness".

This turmoil continues as Olivia says, "being a 'leper' is a hard road to travel, but my family also suffered" as they were "watched carefully" by the "bounty hunter" (15). Her family tries to move and escape the stigmatization they face as a result of Olivia's diagnosis. However, they could not outrun the social ostracization as a new neighbor worked at the hospital for "leprosy" where Olivia was sent. Olivia explains that "whenever she saw my

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<sup>14</sup> Kalaupapa is the "leper colony" established 1866 on Molok'ai as the place which all those diagnosed with Hansen's disease, roughly 8,000 native Hawaiians, were sent to until 1969. See 2015 CNN article, *Taken from their families: The dark history of Hawaii's leprosy colony* and Mouritz's 1916 *The Path of the Destroyer*.

mother, she always said, 'This lady has a girl with leprosy.' My mother almost had a nervous breakdown" (15). In the end, her once happy family becomes haunted by this metaphorical "leprosy". Eventually, one of her sisters disowns her, never speaking about or to her again. Even her mother stopped talking about her. This picture is quite a contrast to the initial, before diagnosis narration which Olivia paints of her family. The lived metaphor of "leprosy" alienates her from her once close-knit family. This is not due to the disease itself but to its monstrous metaphor. The resulting social imaginary effectually turns Olivia into a living signifier of this fabricated monstrosity that is the "leper". She becomes something to fear. The effects are so powerful she is alienated from her once very close family. Her body has been translated into this monstrous metaphor and has, therefore, become an unhomely space which serves to separate her from her own family with whom she was once very connected.

Of her fiancé Olivia reveals that she, never knew "if Les ever found out about me because, a couple of weeks after I entered Kalihi, my family moved out of our house" (10). Such fear around the disease meant not only did Olivia disappear, but her family chose to as well. The patient was of no concern as they must be segregated immediately with no regard for goodbyes. Of her fiancé Les, Olivia says, "[i]ndeed, I never saw him again. Let him hate a lost love" (10). Her diagnosis meant that her marriage would never happen, not because she is too ill, but because of "leprosy". What is truly significant, is not that she is sent away, but her own apathy with the fact Les probably never knew. In this way, Olivia displays the shame being forced upon her. Her diagnosis turns the dehumanizing discourse she hears about "leprosy" into descriptions of her body. This forces her to look at her own body through this dehumanizing discourse transforming it into an unhomely space. Her body

becomes a lived signifier of “leprosy’s” monstrous metaphors not just to society, but to Olivia as well.

Olivia’s alienation from her family illustrates her body as an unhomely space. As her body now represents the metaphor, “leprosy,” it serves as a force separating her both physically and emotionally from her family. While she once remembered nothing but happiness and “beautiful memories” when thinking of her family, she now explains, “[e]verything seemed hopeless” (Breitha 10). After diagnosis, her feelings towards her family have changed from happiness to hopelessness simply because she is now diagnosed with Hansen’s disease. It is not that her family has changed, but what they represent to her is something she cannot have, something she has lost and a place she no longer belongs. The monstrous metaphor of “leprosy” is now transcribed to her body. She is alienated because her body evokes monstrosity and danger as her body itself is understood as the metaphorical “leper”. This then, constitutes what happens when illness, which has a monstrous metaphor, becomes lived for its patients. For the patient, this diagnosis means the loss of family and romance. For the patient, “leprosy” is loss.

Loss is part of both, Olivia’s and Betty’s lived experiences as patients with Hansen’s disease. However, the way in which this loss occurs is, of course, unique to each individual. For example, Betty’s relationships with her family and Robert (her fiancé) are also affected by this diagnosis, but not in the same way as Olivia’s. Both are ostracized from their families. While Olivia’s parents stop speaking of her to avoid their own pathologization, Betty’s parents attempt to hide their, “disgrace” by only telling the truth to a few select people (Martin 15). Betty remembers, “Robert and my parents were adamant; no one must ever know” (Martin 15). Unlike Olivia, Betty’s fiancé Robert is part of those who know the truth. In order to hide this truth Betty was even given a fake name, “Miss Betty Parker”

which she explains as “a name under which, Robert and the family had decided, I was to live while at Carville” (18). For Betty, “leprosy” is a fake identity because the metaphor of “leprosy” renders her too “disgraceful” for her closely bonded family to risk association. As long as no one knows what she has become, as though she has indeed become something else, then all is fine. This is not to suggest fault of her family, but rather, to demonstrate the pathologizing power of a diagnosis that transforms one’s body into a fabricated signifier of monstrosity.

Even though at first, Betty’s relationship with her fiancé Robert remained unaffected, part of which might have to do with the fact he was in school to be a doctor, the relationship eventually meets the same fate as Olivia’s engagement. Betty, unlike Olivia is allowed to go home for Christmas. This kindness actually exposes Betty’s alienation from her family. Betty’s body is an unhomely space because it serves to alienate her from her own family. Her diagnosis transcribes her body with “leprosy’s” monstrous metaphors. For Betty, this causes her to no longer identify with her family, “I was not one with the family anymore. Even Robert was not as he had been” (68). In fact, it is not the physical effects of the illness which make Betty feel uneasy in what once was her home full of happiness, “gaiety and the fun of being engaged”, but rather the lived metaphor of the disease (1). Her family has not changed. This inescapable monstrosity which her body represents disconnects her from her family because she herself feels as though she is this monstrosity. This is not to say she agrees with the fabricated metaphors of “leprosy”. She knows better than anyone the fallacy of these tropes. Rather, her own sense of ‘self’ has been affected by understanding that this is what her body now represents despite its inaccuracy. Thus, her body becomes an unhomely space from which she can never escape.

The dehumanizing rhetoric which transforms Hansen's disease into the monstrosity of "leprosy" is how Betty is made to feel she represents a monstrosity. She confirms this when elaborating, "[d]id [Robert] realize that I, once discharged as totally cured, might still be a hindrance, should our secret ever become known, because of the stigma attached" (Martin 69)? Her alienation is the result of "leprosy" rather than the actual physical effects of Hansen's. In fact, Betty goes on to reveal it is the language, the single word "leprosy," that inflicts monstrosity, and thus, turmoil onto the lives of patients and their families when she writes "[i]n Carville I had seen lives broken by the word leprosy. I had seen families fall apart" (69). Eventually, this is the case for Betty as well when she "demand[s] the truth [from Robert]. 'Do you love me still?' And Robert answered as frankly, in a lost sort of way, 'No. I want to, Betty, but I cannot.'" (69). In the end, it is the metaphorical monstrosity of the disease that breaks off the engagement of Robert and Betty. In this way, "leprosy" and its metaphors force a wedge between the patients and their loved ones. Eventually, the patient's psyche is so fragmented from their body that even if allowed to be physically near those they love, their body remains as a gap which will never completely close.

Both of these autopathographies confirm the permanency of this unhoming as they compose their narratives years after diagnosis and cure. Betty goes on to write *No One Must Ever Know* in 1959, the sequel to her initial autopathography *Miracle at Carville*. In this sequel she tragically speaks directly of the lifelong enduring psychological damage caused by such pathologization stating, "I shall never be able to overcome the horror" of that initial diagnosis ("No One" 26). Thus, blaming not the disease, but the moment of diagnosis as her most horrific moment. She specifically identifies the word "leprosy" as the culprit of this pain. Betty explains, "[t]he ruin was completed with a word—one I have never been able to

bring myself to speak ... The word had cut us away from family life” (“No One” 27). The monstrous language used to describe the disease transposes bodies diagnosed with Hansen’s as “lepers”. This is permanent and life altering because once the body is the object of dehumanizing discourse, there is no going back. Such a diagnosis transforms the patient into a monstrous image, from which they cannot escape. Even if medically cured, they remain monstrous in the eyes of society.

Each of these autopathographies (*Olivia and Miracle at Carville*) expose the moment of diagnosis as an instantaneous transformation into this monstrous pathological ‘other’. This moment for Betty is so shocking she almost faints. Her initial reaction does not show concern for the physical effects of the illness she has, but rather, fear of “leprosy” itself: “Leprosy!” It spread like a stain on my mind. Oh no, not in this day and place! Its horror belonged to Christ’s time, to draped forms and warning bells and perpetual banishment” (Martin 8). Here Betty’s first thoughts go to the monstrous metaphor of the disease before the physical ailments of the disease. What this shows is that the metaphor “leprosy” is the most detrimental to the individual when they are diagnosed. Rather than thinking of what will happen to her body, the pain, a fever, or a cough for example, Betty thinks of the “horror” of “leprosy”. The diagnosis smears this “horror” to her body, “staining” it with this curse from “Christ’s time”. Her body has been transformed into a live manifestation of “leprosy”.

When left alone with this news Betty’s initial reaction is only deepened:

As shock gave way to realization every nerve and muscle in my body leapt and twitched; there was no reason in me, I was just a shivering bundle of fear. If I had been told I would die on the morrow I doubt if the shock would have been so great, in fact death would have seemed simple by comparison. When one died, all was

over, but I had to go on living and fighting a self violated in a mysterious fashion by an insidious disease. (9)

In fact, she would rather die than live as this metaphor. Death is only a physical experience and then you are gone. It is simple not complicated by all that “leprosy” now means for her body. Even the most extreme physical experience, death would be simpler than “leprosy”. It is the monstrous metaphor of “leprosy” which causes her body to shake and twitch attesting to the very real, lived effects of feeling as though she is that monstrous metaphor.

The metaphor itself is a visceral lived experience for Betty. Visceral as in what Dolphin-Krute suggests as “having to do with the center of the body” a penetrating lived experience (47, 86). Betty’s reaction to the metaphors of “leprosy” alone reveals this visceral nature. The ability of the metaphorical to become the center of the body, the lived reality for the patient, is exemplified through Betty’s lamentation that she must “go on living and fighting a self violated”. Above all else, this diagnosis has violated her sense of ‘self’ at its core, instantaneously fragmenting it from her body. Her body has become something with which she can no longer bear to be identified. Her body is now an unhomely space where her ‘self’ struggles to exist.

Betty’s continues to divulge this moment of diagnosis as immediately altering her own sense of ‘self’:

I thought back to the Bible, to old books and old words—and before my eyes, staring into the dark, appeared afflicted creatures shrouded in rags walking down endless roads, ringing little bells to warn all within hearing to get out of way before the cry: “Unclean.” I was not unclean! I who had braved family protest each week fussing with nails and hair, who loved clothing starched and sweet with sun. “Little



Priss” the family had called me from my earliest years—the family I was now to be removed from as “unclean”. (9)

In her attempt to retrace her life up until her diagnosis she implores the question, how did this happen? She was so clean she was a “priss,” pointing to the fact that her ‘self’ image does not fit the new image forced upon her of unclean. Here again, it is not the physical effects of the disease, but the metaphor itself that causes her grief. It is this monstrous metaphor that causes a fracturing between her mind and her body. In a matter of seconds, her body has become what Bhabha describes as an “unhomely” space (9-10).

Part of this going back to the beginning, before the diagnosis, for each of these women may also represent debunking of the religious metaphor of “leprosy” as a curse. Betty embodies this motive asking directly after her diagnosis, “[w]hat in my nineteen happy years, had betrayed me to this horror out of the Dark Ages” (10)? In Betty’s narrative she retraces her life up until nineteen as she attempts to answer this self-imposed question: “How has this happened, and why, to me?” (10). Pointing out the normalcy of herself and her life she admits to searching for a reason for why she has been touched by this “evil”: “Nineteen. I searched those years and I search them still, finding nothing in them but the purest happiness, the sanest, healthiest living. Nowhere along the road, hunt as I might, could I find any indication of a shadowy place where this evil thing, reaching out, had touched me” (Martin 13). Again, through this illustration of a happy and healthy normal life, Betty contrasts her ‘self’ and her life with that of “leprosy”. These are the things which she feels have been altered by this diagnosis. This inner turmoil demonstrates the ability of a metaphor to become a lived experience. The metaphor of the disease replaces the individual’s sense of ‘self’ with an idea of monstrosity because the body has become a

monstrous metaphor, and therefore, an unhomely space. In this case, “leprosy” transforms the patient’s body, and therefore, their ‘self’ into a “leper”.

Olivia’s narrative also emphasizes her moment of diagnosis as instantaneously creating her body as an unhomely space, altering her sense of ‘self’. For Olivia it is also “leprosy” which is more threatening than the physical symptoms. She describes that “suddenly the whole world changed. I was changed instantly from Olivia Robello who was happily waiting to be married, to Olivia the frozen nothing. I felt alone and so numb ... I couldn’t speak... I decided that I wanted to kill myself” (Breitha 7). Just as Betty’s desire was to die instead of live as this metaphor, Olivia in this moment of diagnosis would also rather die.

This embodiment of the metaphorical “leprosy” is made clear in Olivia’s narrative after she fails to find poison and kill herself. She says, “my little niece, who was my little darling and always crawled to where I sat, tried to climb into my lap. I pushed her away and told her mother to keep her away from me. See, I already felt like a “leper” – belonging no longer with the ones I loved” (Breitha 7). She begins to fear her own body. She sees herself as a “leper” which immediately causes her to feel alienated from those she loves. Her body has become an unhomely space. She cannot even feel safe in her own skin as she refuses to touch her family out of this fear. Betty also has the same fear, “[i]ts very name filled me with panic, still I had been frantic to get away from all those I loved” (16). These descriptions uncover that the patients themselves come to be alienated from their bodies. Olivia and Betty suddenly see their bodies through the gaze of “leprosy’s” demonizing discourse as soon as they receive the diagnosis. Both bodies are now figures of the metaphorical image of a “leper” in the social imaginary, as well as in their own minds. Their

body is now an unhomely space for their 'self' as they fear what it might do to those they love.

This internal unhoming is further evidenced when Olivia says, "There is no way in this world to tell anyone how I felt. The utter hopelessness. I looked at that baby. She was a stranger. My sister was a stranger. The room was not where I should be. I was a stranger. I felt dirty, sinful, untouchable, ugly. No tears Just disbelief. My tears were burning in my heart, but I could not cry" (7). First, she is alienated from her family as they appear as strangers. Suddenly, she is not where she belongs. Just from the diagnosis, she feels so different, that her family and her own sense of belonging to them is drastically distorted. The root of all of this lies in the fact that Olivia ultimately feels unhomed from her own body as she turns all of this alienation inwards when saying, "I was a stranger". It is the fact that she, herself, is no longer anything she recognizes that results in this alienation from her family which is so intense it destroys her sense of belonging with them. Finally, she solidifies this erasure of her sense of 'self' by the embodiment of the metaphorical "leper" when she admits that now she feels "dirty, sinful, untouchable, ugly". All of these adjectives historically tied to the metaphorical trope of a "leper" now force themselves upon her. At this point nothing but the diagnosis has occurred, she shows no visible signs of the illness. All of this internal unhinging is the sole result of the monstrous metaphor that transforms Hansen's disease into "leprosy" and translates the patient into the pathological 'other', the "leper".

Through this drastic change in tone and descriptions of themselves and their relation to those they love, both Olivia and Betty reveal the power of diagnosis to alter one's 'self' image and one's life in a multitude of ways. This again, speaks to the multiplicity of illness (Mol 30-31). Therefore, these narratives illuminate the importance of recognizing that an

illness is more than just its medically defined symptoms. Through adding the patient's voice to the archive, as these autoethnographies allow, a more complete understanding of "leprosy" is possible. For these patients, illness has altered their identity. This drastic change and alteration of these patients' lives in their entirety illuminates the power and lived reality of the metaphor "leprosy". Even as it is a metaphor, diagnosis renders it lived for the patient.

This embodiment of the metaphorical "leper" is brought forth even more in Olivia's telling of her life in Kalaupapa, the "leper colony" on Molokai: "Wherever we went in Kalaupapa, or in Kalihi Hospital, there were signs telling us where we could or could not go and what we could not touch or whom we must not touch" (25). If ever there was a clearer representation of biopolitics this narration demonstrates the potentiality of medical discourse to control the individual through their bodies.<sup>15</sup> Olivia echoes this biopolitical control when she says, "Once declared a patient, our minds became the property of the system, for a while anyway. Then, for a few years we were brainwashed, sometimes right up front, sometimes more subtly" (25). She feels as though her mind is quite literally controlled from the moment she became a patient. Becoming a patient renders her mind vulnerable to control. She is made to feel less than human, controlled in aspect of her life, where she can go and what she can touch, through her illness.

This dehumanization is elucidated through Olivia's narrative when she compares her own situation to that of animals. This animalistic comparison is the result of her treatment and of hearing her own body described in such language. This is the lens she has been given to understand her body and her life. When she describes the visitor building, "This place had

a concrete floor and windows ... There was a six foot chain link fence between the patient and his or her visitor...I called it the ‘dog Kennel’” the animal like treatment is clear (40). The constant inhumane treatment only continues to enforce this medicalization which aims to dehumanize and unhome the patient from their most intimate of homes, the body. This unhoming as a result of “leprosy’s” metaphors is highlighted when Olivia explicitly says, “as I’ve already mentioned, patients at Kalaupapa were not only haunted by what was happening to them physically, but were also held down to the ground by the rocky fists of rules and regulations, which often seemed to be a result of sheer whim rather than medical necessity” (47). The potentiality of a monstrous metaphor to result in literal control and power over an individual is revealed by these unfounded regulations. In this way, the individual who constitutes the metaphor as lived also justifies the inhumane treatment of their body as legitimate because they are then not human, but the monstrous “leper”. Their body is an unhomely space allowing for inhumane treatment and forcing the degradation of the ‘self’ to a dehumanized, and therefore, debilitated level.

As Olivia talks about the effects of the disease on her body the results of this dehumanization are exposed, “When I gently put my right foot on the floor, it would not lie flat...actually, it turned inward. I was a cripple. It was not in that condition before the surgery” (58). The way in which she describes what happens suggests betrayal by her own body. In this particular instance, the doctors also betray her as she goes on to say:

I was very, very angry at what had happened to my foot. I may be wrong, but I think there may have been a mishap during my surgery. However, everyone denied that

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<sup>15</sup> Here I refer to biopolitics, as coined and defined by Michel Foucault in *Discipline and Punish*, as a means to control people through their bodies thus enabling an individual’s body as a tool of governance. See Foucault, Michel. *Discipline and Punish*. Translated by Alan Sheridan, Second Vintage Books Edition, Vintage Books A Division of Random House, Inc., 1995.

anything went wrong. I will never know for sure, but I am chained by it now. Oh well, I'm only a "leper" and not worth worrying about. But I do worry. (Breitha 58)

She will never get justice because she is a "leper" and not deemed worthy of such an answer. Olivia's own employment of the monstrous trope, "leper" to describe her own body shows the psychological degradation that occurs as a result of constantly being dehumanized. Constantly made to feel less than human and imagined as a "leper" her body is an unhomely place, pathologized as a monstrous 'other'. However, in this moment she says, "but I do worry" contrasting her own humanity with the monstrosity of her reality. With these words, she challenges her pathologization articulating that she is a person trapped in this unhomely body that renders her vulnerable to what is a fictitious monstrous metaphor. Finally, this connection between body and identity is validated when she explains that now with this impairment, this bodily injury, her identity is that of a cripple. Her sense of 'self' is impacted again by her physical body. Thus, she exemplifies the role the body plays in one's social identity as well as one's internal sense of 'self'.

Betty echoes this forced embodiment of "leprosy's" monstrous metaphors when she speaks of her body as something that has betrayed her, and therefore, she tries "to learn all I could about the body that had betrayed me, and learn its functions that I might work towards a cure" (25). At this moment Betty exhibits a fragmenting of 'self' and body as she talks about her body as a separate object. Like Olivia, she feels her own body has betrayed her. Given this sense of betrayal, one can further understand how an individual's body can be made an unhomely space.

As a result, Betty comes to work in the lab at Carville where they analyze the blood of patients for *Mycobacterium leprae*, which because of "leprosy's" pathologization can be argued to be more than just a bacteria, but the signifier of a "leper". She illuminates the

ability of blood to serve as a code for what the whole human body represents, “with greater understanding I looked through my test tubes and glasses into the human segment that was Carville. That blob of blood I was breaking down was not plasma; it held the soul of a fellow human who spoke, wept, tried to be brave, even as I” (Martin 70-71). This description brings to the surface the interconnection between the body and the person as well as the metaphors of “leprosy”. The blood is not just blood. It is the soul of a human. She illuminates the danger that occurs when society conflates these as one and the same. Her illness, enabled by its monstrosity, when used as a fragment of her whole body to represent her entire identity, erases her humanity.

In her pathography, she speaks poignantly to this potentiality of the metaphor of “leprosy” to erase the human in the patient. She highlights how this is achieved through this single word, “leprosy” and from this, the individual becomes a “leper”. Betty writes, “We who have the disease called “leprosy” know that the ravages of its stigma are far great than those of its germ” (227).<sup>16</sup> Once again her pathography points to the greatest struggle of this disease as the effects of its metaphor on the patient. The power of this single word to remove the individual from their body is a key part of what Betty experiences, “Why does the MEDICAL WORLD, which has the power to change my unfortunate predicament by ONE LITTLE WORD, refuse to remove my disease from the stigmatic, generic, biblical term “leprosy” when it has given all the other diseases which “leprosy” covered in the Bible more scientific names?” (234). In this piece which she writes for the *Star* and includes in her autopathography, she laments, this single word fragmented her whole sense of ‘self’. Declaring that it had the capacity to, “break [her] into pieces with ONE LITTLE WORD”

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<sup>16</sup> This quote, from Betty Martin’s auto-pathography, was written alongside Stanley Stein in an editorial for the *Star - Radiating the Light of Truth on Hansen’s Disease*, a newspaper Stanley started in Carville in 1941. See *Louisiana State University Libraries Special Collections*.

(Martin 234). For Betty, this disease is really all about the monstrous discourse which surrounds it and to which she is subjugated. The power of this control and the turmoil of this disease are all because of the single word “leprosy”. Its transformative ability means the individual becomes a living representation of the metaphorical “leper”. This monstrous metaphorical figure is now real and the patient is its manifestation.

As a result of this dehumanization by “leprosy’s” monstrous discourse, both Olivia and Betty seek to try and cure this aspect of the disease. They both write their autopathographies to try and correct this stigma. As Olivia pleads, “I don’t understand. There is so little real respect by the State for patients as people. I have written my story because of my desire to let people know that patients are first of all people, very real people. We live life, too. We are not from another world. We are here.” (83). After this forced embodiment of this metaphor which has become inseparable from the disease, Olivia like Betty, seeks to set the record straight and speak out against the dehumanization of patients as “alien” or “unhuman”. After all, this part of Hansen’s disease cannot be cured by any drug regiment, but by a steady deconstruction of the discourse used to form the metaphor of “leprosy” which supports the figure of the “leper”.

In fact, in the last pages of her autopathography, Olivia includes answers to commonly asked questions about Hansen’s disease. One of these being “What is the correct terminology for the disease?” her response follows:

Hansen’s Disease is the official term in Hawaii and also advocated by the National Hansen’s Disease Center in Carville, Louisiana. However, the term “leprosy” is used throughout most of the world. The question of terminology is widely debated, proponents of each term citing a number of reasons for their preference. However, it is universally agreed that the term “leper” is totally inappropriate and should not be



used. Dictionary definitions of the word “leper” include the adjectives “immoral” and unclean”. Persons with leprosy are neither of these things. (Breitha 104)

Here Olivia directly addresses the metaphorical “leper” as ascribing inaccurate and negative adjectives to those afflicted with Hansen’s disease. In doing so, she illuminates the power of both discourse and the metaphor it constructs as controlling individual identities through rendering the body an unhomely space. She stresses the importance of realizing what this term means for those who have the disease. The inclusion of this as her final statement stresses the need to deconstruct this monstrous discourse.

Additionally, Betty’s autopathography includes the narrative of how the *Star* began capturing this aim to deconstruct the monstrous discourse around Hansen’s disease. For example, on the inside cover of each copy of the newspaper, a piece entitled *Facts That You Should Know About Hansen’s Disease* was printed. This piece began:

In order that leprosy may be dealt with successfully on a comprehensive scale and before any large proportion of early cases will come voluntarily for examination, there must be a change in the attitude of the public towards the disease. Any scheme for the control of leprosy will depend for its success on an educated public opinion. (Martin 212-3)

Betty points to the cure for this disease, at both the physical and mental registers, as dependent on more than drugs. The cure must also include a new discourse and public knowledge capable of eradicating the monstrous metaphors of “leprosy” that enables such dehumanization.

It is through the autopathography that one can understand the impact of what monstrous medical metaphors do to the patient. Autopathographies then serve to bring the patient’s voice to the narrative of illness, and therefore, this genre alone can illuminate the

process of becoming ill as one that threatens to unhome the 'self' from the body as a result of dehumanization. This medical dehumanization is the direct result of the metaphor becoming lived for the patient. A diagnosis of Hansen's disease is not just a diagnosis of an ailment, but a forced embodiment of the monstrous metaphor "leprosy". As a result, the body becomes an unhomely space alienating the individual internally, as their 'self' does not identify with their now monstrous and dangerous body, and externally, from society, including those they love. In this way, "leprosy" is not just *Mycobacterium Leprae*, but a loss of love, family, home and happiness. It is multiple, as Mol suggests, because it changes all of these things for the individual. For the patient, this is Hansen's disease, a bodily betrayal to which society applies a monstrous metaphor that renders them a pathological 'other'. This is a powerful realization that signifies the role of autopathographies as enlightening the lived realities of illness in a way that highlights illness as not only clinical, but lived, emotional, and metaphorical. Ultimately, this speaks to the need for more holistic medicinal approaches which might better avoid the resulting medical bodily unhoming. In this way, it is possible to see the potentiality of autopathographies to help affect social change in instructing medicine to care about the whole experience of illness by demanding attention be paid to the patient voice.

## IV. Conclusion

This thesis has taken a multimedia archival approach in looking at the history of Hansen's disease to consider what happens when medical discourse becomes dehumanizing. The texts analyzed in this thesis should be thought of as a snapshot of what is a much larger archival collection. Together, these specific documents shed light on a complex narrative of how medical discourse can become dehumanizing. The extreme case of Hansen's disease shows how a clinical diagnosis can be mobilized as a social condition that justifies biopolitical governance. This evolution is enabled because Hansen's disease as a diagnosis instantly ascribes the monstrous metaphor "leprosy" to the patient's body. As a result, they become the monstrous figure "the leper," and are then the subject of its monstrous discourse. While I do not wish to suggest that all medical diagnosis has this effect on the patient, I do hope that this analysis has demonstrated a process of medical dehumanization that is possible with any illness if it evokes a stigmatizing social condition.

The intention of this research is to emphasize the importance of holistic medicinal approaches that consider the patient a person and the disease multiple. This multiplicity of disease includes not only the physical impact of the illness on the patient, but also the social impact as part of the lived experience for the patient as a person as well. This means it is necessary that the practitioner, in approaching the patient, considers this full impact of the illness on the patient. In this way, better treatment can be achieved as a greater understanding of the patient's condition can be considered in determining how to care for the patient.

While this thesis focuses on "leprosy" and the "leper colonies" of Carville, Louisiana and Molok'ai, Hawaii the story of "leprosy" is a global one. Nearly every country such as

China, Australia, South Africa, Senegal, Norway, Germany, France, Spain, Japan, Brazil and India to name a few, has at some point in time, had a history with this monstrous metaphor.<sup>17</sup> Additionally, “leprosy” as a monstrous disease is part of the global imaginary. For example, there have been 20 different international “leprosy” conferences since the first one in Berlin, 1897. As global conferences numerous practitioners and experts of disease control and governance from various different countries all met to approach controlling this feared disease. This symbolic heft of “leprosy” as a globally visible disease with overwhelming social impacts across historical contexts, then makes this study a pursuit of a global trope. Furthermore, the fictional stories of “leprosy” and the “leper” can be found in multiple countries’ cultural archives, as discussed in chapter one.<sup>18</sup> Therefore, Hansen’s is not just a global disease, but “leprosy” is a global metaphor, and the “leper” is a global trope which elevates the analysis of this thesis to the register of the global. Even as the texts analyzed in this thesis only fall under the umbrella of the United States, the multiple emergences of “leprosy” on symbolic and material levels make comparative analysis critical to the study of this metaphor. This analysis only provides a small window into this global narrative of dehumanizing through disease.

Through analyzing historical documents such as government policies, reports by contemporary doctors, literary narrative, and newspapers for how “leprosy” and those with Hansen’s were discussed, the construction of a social imaginary which envisioned the disease monstrous is uncovered. The historical archive then serves as the record for how a clinical diagnostic can become a social condition for the patient if a monstrous, fearful

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<sup>17</sup> *International Leprosy Association – A History of Leprosy*, is an extensive online archive that serves as a starting point into the global history of “leprosy” and the monstrosity it enabled. <https://leprosyhistory.org>

<sup>18</sup> Novels such as, *The Samurai’s Garden* by Gail Tsukiyama (1994), *The Pearl Diver* by Jeff Talarigo (2004) and *No Ordinary Day* by Deborah Ellis (2011) demonstrate the global imaginary of “leprosy”. See Chapter 1 for more titles.

imaginary is constructed. These documents demonstrate how Hansen's disease becomes "leprosy," and the patient becomes a "leper" through criminalistic and animalistic rhetoric. As was seen in the Hawaiian and Carville cases, the "leper" was described as a figure to fear. The documents detailing the concern of the disease in relation to Hawaii state that "every leper is a possible source of danger to all with whom he may come into intimate and prolonged contact" (Morrow 585). These are not sick people, but a danger to society. They describe the patients as "clean, a suspect, or a leper" criminalizing the body of the patient (Morrow 586). Similar criminalizing discourse was also found in the documents from the Carville case as Dr. Faget demonstrates when trying to provide hope for those with the disease stating, "An ever-increasing number of patients is being discharged from leprosariums as 'arrested cases' and no longer a menace to the public" (Faget 1871).

Similarly, the patients at Carville were also consistently referred to as "lepers," using this term evokes all the monstrosity linked to "leprosy". Even when the documents tried to disguise this pathologization, by trying to show they were providing them care, they still worked within these monstrous terms for example, "communities are, as a rule, absolutely unprovided with proper means for the care, segregation, and isolation of lepers" (Care 7). These documents all show the construction of an imaginary that supports a monstrous figure the "leper". This metaphorical figure then became a real monster through the patients diagnosed with "leprosy". Certain 'other' bodies, such as the Native Hawaiian, were constructed as a body to fear because of its potential to become a "leper," as the danger of "leprosy" was clearly framed as a threat from the foreign country/body. The Hawaiian case represents just one example of how the body of the 'other' was racialized through disease.

The successful fabrication of a monstrous metaphor then enables the clinical diagnostic to become a political tool as the disease provides a justification for governance

over that group, or those individuals whose bodies are considered a threat either because they have the disease or because they *could* have the disease. As Jeffery Cohen's first thesis states, "the monster's body is a cultural body," it is fabricated by and therefore represents society's fears (4). In this specific case, the fear of the 'other' could be mobilized by ascribing a dangerous disease to the unfamiliar or foreign body, thus providing a medical justification for that fear. Chapter 1 clearly highlighted the rhetoric which framed "leprosy" as a threat from "uncivilized countries," a dangerous disease being "imported to the United States" (Care 3-7). In affect this created a social condition which feared the 'other' body as one that could be harboring a dangerous disease, or even worse, a body that could actually be that of a "leper". In this way, a fearful narrative of the 'other' was created through a disease. The construction of a monstrous pathological 'other' is then achieved, and as a result, it only takes a diagnosis to ascribe all of this dehumanizing monstrosity to the individual.

This is where the autopathography becomes undeniably vital to the medical archive as it is through their pages that the patient voice is recorded. It is only by including the autopathographies of Olivia and Betty that the impacts of Hansen's monstrous metaphor "leprosy" can begin to be understood as a kind of medical dehumanization. These women describe their moment of diagnosis in a way that illuminates it as a critical moment for the patient. Olivia immediately "felt like a 'leper' – belonging no longer with the ones [she] loved" (Breitha 7). While Betty explains the experience as "a self violated in a mysterious fashion by an insidious disease" (9). The suddenness of their visceral and core shaking reactions of this diagnostic moment shows it has the potentiality for mental violence as it causes, for them, a kind of internal alienation. As Chapter 2 demonstrated their immediate reactions of a diagnosis of Hansen's disease included thoughts of the biblical damnation

associated with “leprosy,” the idea of being “unclean,” as well as the horror of becoming the monstrous creature the “leper”. The fact that their stories of living with Hansen’s disease actually read as an experience of living as a pathologized body reveals the social condition which “leprosy” brings as also part of what these patients have to contend with from the moment they are diagnosed. This reveals the multiplicity of disease as well as the moment of diagnosis as critical in the process of becoming a patient (here I am referencing Annemarie Mol’s *The Body Multiple*, 2002). This extreme case of “leprosy” demonstrates how this can all serve to rupture the individual’s ‘self’ from their own body. As I have argued, this alienation can be thought of as an internal “unhoming” in reference to Homi Bhabha’s cultural “unhoming” (*The Location of Culture*, 1994).

This analysis then highlights the moment of diagnosis as one that should consider the multiplicity of disease. It is a moment when the repercussions and many ways the disease affects the patient, beyond the physical affects, should be considered. Not that the social condition can be controlled by the practitioner, but that the practitioner should be aware that this is also part of what they are diagnosing. After all, it is through diagnosis that the practitioner can unintentionally ascribe social stigma to their patient’s bodies. Just as the practitioner considers how to approach the patient medically, physically and biologically as a result of the diagnosis, they should also consider how might this mentally affect the individual. Furthermore, they must ask how does this diagnosis affect this individual’s daily life? Not only will such considerations minimize the potential for mental violence but they will lead the practitioner to consider a holistic approach.

Ultimately, the gap which autopathographies fill make them a necessary part of understanding the process of becoming a patient and more pointedly, serve to relay the lived experience of being ill. These narratives should then be especially significant to those

working in the healthcare industry as they are the ones who care for the sick. As these narratives bring forth the patient voice as unmediated as possible, they enable the multiplicity of the body and illness to be recorded and recognized within the archive. As a result, they serve to undercut the social stigma of monstrosity that can be attached to certain diagnoses. They hold open a powerful window for assisting medicine in achieving a holistic approach and thereby, improving the experience of becoming a patient which is otherwise quite alienating.



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